DRAVET Syndrome UK

FAMILY GUIDE

Everything you need to know about living with Dravet Syndrome

Welcome to the Dravet Syndrome UK *Family Guide*

At Dravet Syndrome UK, supporting families is at the heart of everything we do. Our *Family Guide* is for everyone affected by a diagnosis of Dravet Syndrome. Whether you're a newly diagnosed family or have been caring for a child or an adult living with Dravet Syndrome for many years, you'll find information, advice, practical tips and insights to help you on every step of your journey.

For more than 14 years Dravet Syndrome UK has been the only UK charity dedicated to improving the lives of families affected by this rare condition. Our *Family Guide* is the culmination of knowledge, lived experience and insights that we have gathered over the years, informed by the real-life experience of families, the expertise of our world-class Medical Advisory Board, and research about Dravet Syndrome.

The *Family Guide* is a comprehensive resource, reflecting the complex nature of Dravet Syndrome and its effect on every area of life. Don't feel you've got to read it all in one go – it's there to dip in and out of as you need.

Receiving a diagnosis of Dravet Syndrome can be a scary time, so if you are a newly-diagnosed family, the first section 'About Dravet Syndrome' is a helpful introduction. The other sections of the guide cover every aspect of Dravet Syndrome in detail – from the characteristics of the condition and advice on managing these, to dealing with the challenges faced in everyday life.

Above all, we hope this *Family Guide* reassures you that, wherever you are in your journey, support is available. You're joining a vibrant, welcoming, Dravet Syndrome community, with many families who are going through similar challenges and experiences. Living with Dravet Syndrome can be a tough journey, but you're not alone.

At Dravet Syndrome UK, we're always here for you and your family. If you have any questions, please call us on **01246 912421** or email **info@dravet.org.uk**. You can also visit our website: **www.dravet.org.uk**

The Dravet Syndrome UK team

Note: The information in this guide was compiled by Dravet Syndrome UK with input from our expert Medical Advisory Board. All information was correct at time of publication in January 2023.

About Dravet Syndrome UK

Dravet Syndrome UK was established in 2009 by a group of parents who came together looking for support, resources and information relating to this rare condition. Today, much more is known about Dravet Syndrome and we are privileged to support many families affected by the condition in England, Wales, Scotland and Northern Ireland.

We are the only registered charity in the UK dedicated to improving the lives of families affected by Dravet Syndrome. Our mission is to bring hope to families through support, education and medical research.

We support families in many different ways, including providing practical and emotional support, advice, and financial grants including our Seizure Monitor Fund and 16+ Assistance Grant for young people and adults. We bring families together, whether online through our community forum or via our Annual Family Weekend Away, to help overcome the isolation of living with a rare and complex condition such as Dravet Syndrome.

We take a leading role in raising awareness about Dravet Syndrome and educating professionals, with the aim of improving diagnosis and care for everyone affected by Dravet Syndrome. The generosity of our fundraisers and donors enables us to fund medical research, for better understanding of the impact Dravet Syndrome has on family life, and to improve how we diagnose, treat and manage the condition.

All our activities are underpinned by guidance and support from a world-renowned Medical Advisory Board.

At the time of writing, our Medical Advisory Board is:

Professor Helen Cross OBE
Professor of Neurology (Chair)

Professor Sameer Zuberi
Consultant Paediatric Neurologist

Professor Andreas Brunklaus
Consultant Paediatric Neurologist

Professor Sanjay Sisodiya
Professor of Neurology

Dr Elaine Hughes
Consultant Paediatric Neurologist

Professor Mike Kerr
Clinical Professor Emeritus

Amanda Tomalin
Paediatric Epilepsy Clinical Nurse Specialist

Dr Julia Aram
Consultant Neurologist and Epilepsy Lead

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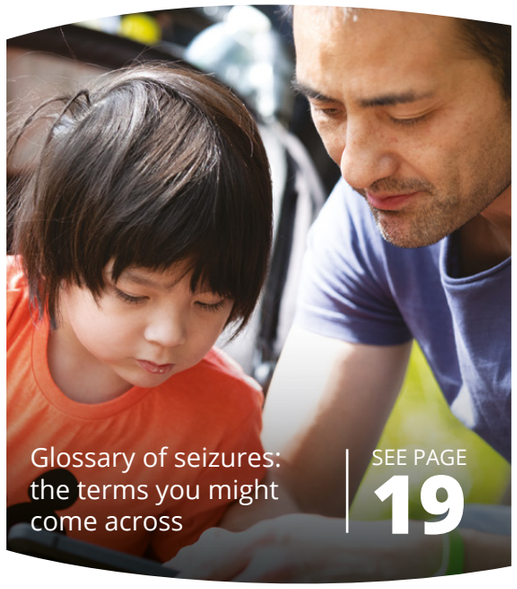

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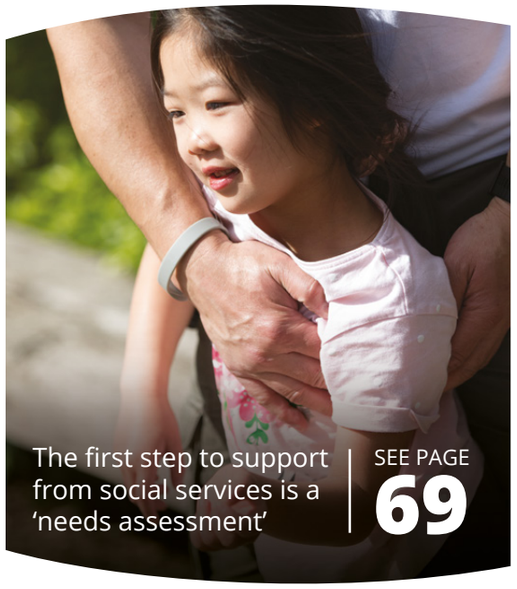

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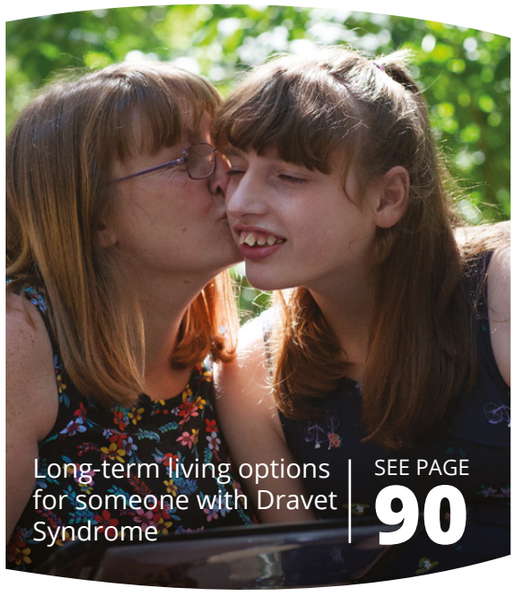

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PART 1

ABOUT DRAVET SYNDROME

1. What is Dravet Syndrome?

Dravet Syndrome is a rare, life-long and life-limiting neurological condition. Around one in every 15,000 babies in the UK will be born with Dravet Syndrome.

It's often described as a form of epilepsy. However, epilepsy is just one part of Dravet Syndrome. As well as severe, difficult-to-control seizures, children and adults with Dravet Syndrome have varying degrees of intellectual disability and a spectrum of associated conditions, known as 'comorbidities'. These can include autism, ADHD, challenging behaviour and difficulties with speech, mobility, eating and sleep.

Every child or adult with Dravet Syndrome is different. The range and severity of symptoms vary from person to person – which is why you'll see that we often talk about Dravet Syndrome as being a 'spectrum' condition. However, for all, the condition is complex and can be unpredictable.

Dravet Syndrome: past and present

Dravet Syndrome was first described in 1978 by Charlotte Dravet, a childhood epilepsy specialist based in Marseille, France. Just over 10 years later, in 1989, it was recognised as an epilepsy syndrome by the International League Against Epilepsy.

You may also see Dravet Syndrome described as 'Severe Myoclonic Epilepsy in Infancy (SMEI)', which is now an out-dated term.

In recent years, understanding of Dravet Syndrome has increased dramatically. There's now more focus on addressing the comorbidities, as well as the seizures. Diagnosis has increased, and while it was originally seen as a childhood syndrome, Dravet is now recognised as a life-long condition, leading to more adults being diagnosed as well as children.

2. What causes Dravet Syndrome?

Dravet Syndrome occurs when one of the genes in a part of the brain, known as the sodium ion channel, doesn't function as it should. The movement of sodium ions in and out of nerve cells helps to control electrical messages in the brain. So, a faulty ion channel gene can cause seizures, intellectual disability and the spectrum of comorbidities that we see affecting people with Dravet Syndrome.

Which genes cause Dravet?

More than 85% of people with a diagnosis of Dravet Syndrome have a change (mutation) in the gene known as SCN1A (short for sodium channel alpha 1 subunit). But having a mutation in the SCN1A gene doesn't necessarily lead to Dravet Syndrome. There is a spectrum of SCN1A conditions and Dravet Syndrome lies at the severe end of that spectrum. Other SCN1A mutations are associated with less severe forms of epilepsy, such as Genetic Epilepsy with Febrile Seizures+ (GEFS+).

Around 10 to 15% of people with Dravet Syndrome either have no detected SCN1A mutation, or have mutation(s) in genes other than SCN1A (including CN2A, SCN8A, SCN1B, PCDH19, GABRA1, GABRG2, STXBP1, HCN1, CHD2, and KCNA2).

Much research is currently taking place to help us better understand the relationship between the type and placement of genetic mutations and the severity of the condition. Scientists can predict whether a SCN1A mutation will lead to Dravet Syndrome or a less severe form of epilepsy. However, at the time of writing, there's no evidence to show any correlation between the type of mutation (and where it occurs) and the severity of Dravet Syndrome.

A spontaneous gene mutation

We know some families worry that they are somehow responsible for their child's genetic condition. However, in around 90% of cases, the Dravet gene mutation is 'de novo', which means it happens spontaneously and is not inherited from parents.

For the approximately 10% of people who do carry the SCN1A mutation, it's important to know that this does not mean that they, or their children, necessarily have Dravet Syndrome.

Gene mutations happen in everyone, it's part of being human. In most cases, the fact that they happen to important genes, like SCN1A, is simply random.

For links to more detailed information on the genetics of Dravet Syndrome, visit the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

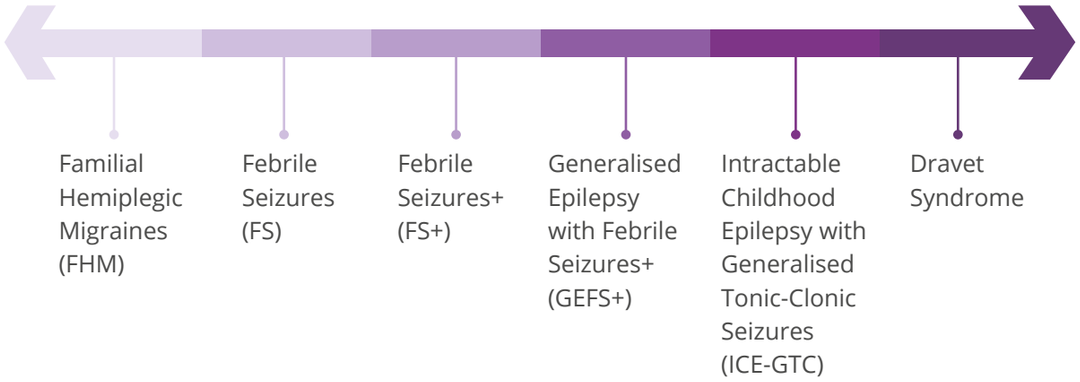
3. Is Dravet a clinical or genetic diagnosis?

Dravet Syndrome is, first and foremost, a clinical diagnosis. This means it's diagnosed from reported signs and symptoms, rather than diagnostic tests. In the UK, the clinical diagnosis is based on the age symptoms start, types of seizures, and the way the condition develops.

It can be very helpful to find out whether people with this clinical diagnosis also have a genetic mutation associated with the underlying causes of Dravet Syndrome.

The genetic test for Dravet Syndrome is normally a simple blood test, available free of charge via the NHS in the UK. The type of test may vary depending on where you are in the UK. A genetic test can tell you whether Dravet Syndrome is inherited or has arisen spontaneously. If it has been several years since the person was tested, it may be worth requesting that they are tested again, particularly as technology is improving all the time.

The spectrum of SCN1A conditions



A 'positive' test for a genetic mutation, sometimes called a 'confirmative' test, can help prevent misdiagnosis and avoid further unnecessary tests. With a positive test, you can make better-informed choices about treatment and therapies.

Genetic testing has benefits at every age:

- For babies and infants, because it's hard to get a clear diagnosis of Dravet Syndrome from symptoms alone.
- For adults, because the early signs and symptoms of Dravet Syndrome may be lost from their medical history, making the condition harder to diagnose. Or, they may have been misdiagnosed, so a genetic test can give them the correct diagnosis and mean their condition can be better understood and managed.

A 'negative' test for a genetic mutation doesn't rule out a clinical diagnosis of Dravet, it just means that no mutation was found.

Genetic counselling

Despite its many benefits, genetic testing can be an emotional time for families and genetic counselling is always recommended. An important aspect of genetic counselling is that it provides support with the emotional and family implications of a genetic condition. This could be support with coping and adjusting to a diagnosis or help with how to tell other members of the family about the possibility of the condition being passed on.

To receive genetic counselling, your neurologist or paediatrician will need to refer you to your local NHS Regional Genetics Centre or to a private provider. More information about genetic counselling is available via the NHS website, including a list of NHS genetic centres.

For links to more detailed information on genetic testing, visit: **www.dravet.org.uk/family-guide-resources**

4. We have a diagnosis, what happens next?

Receiving a Dravet Syndrome diagnosis can feel devastating. At the same time, a confirmed diagnosis helps to provide an 'answer' to a period of turmoil and uncertainty which, for some families, may have lasted years.

"We felt devastated and couldn't accept this was happening to our baby girl. Right now, we are still finding each day hard and are always constantly watching over our daughter. We are just taking things day by day and the support of our friends and family is helping us cope with this better."

Dad to a one-year-old with Dravet Syndrome

"We came across Dravet when our daughter was about 15 months old, as we were not convinced that her condition was 'just' epilepsy... Nine months later we finally had the diagnosis. Although we knew deep down what was coming, seeing it in black and white was gut wrenching. As parents, you go through a grieving process for the life you thought you would have."

Mum to a seven-year-old with Dravet Syndrome

> Our son had his first seizure when he was three months old, a lengthy tonic-clonic seizure lasting approximately 40 minutes, which required an emergency night-time visit to hospital. This became the pattern for years – frequent prolonged seizures, stays in hospital, referrals to larger hospitals with epilepsy specialists, tests and more tests and cocktails of various epilepsy medications tried. He was diagnosed as a child with generalised epilepsy. It wasn't until he was 36 years old that we finally had a genetic test and a Dravet Syndrome diagnosis. This came as a great relief and with better, more targeted drugs as a result, he is having less seizures and his ability to learn has increased.

Dad to an adult with Dravet Syndrome

A diagnosis means you and your family are not alone. The Dravet Syndrome community and Dravet Syndrome UK are here to support you. Get in touch at **info@dravet.org.uk**

Diagnosing your child's/adult's condition is the first step to being able to improve life for them and the entire family. It means there is a better chance of your child/adult receiving the right medications to treat Dravet Syndrome, which will, hopefully, lead to better seizure control. A diagnosis will also make it easier to access additional therapies to help with comorbidities, and practical and emotional support.

5. What's my child with Dravet Syndrome going to be like?

One of the questions we're most frequently asked, especially by newly-diagnosed families, is "What's my child going to be like?"

We can't tell you exactly what the future holds for any child or adult. While there are many things people affected by Dravet Syndrome have in common, there are also differences – for example, in the range and severity of symptoms and comorbidities. (We provide more detail about these in Part 2 of this guide). What we can do is help prepare you for the road ahead by sharing examples and insights from families going through similar experiences to you.

As scientists advance their understanding of Dravet Syndrome and its causes, more sophisticated diagnostic information may become available in the future that will help predict what an individual with the condition will be like.

Parent/carer stories

Throughout this guide, we include quotes from parents and carers of people living with Dravet Syndrome. They share their diverse experiences, including the twists and turns, tears and laughter that their lives entail.

"Thomas is kind, loving and gives the best hugs! He leaves an impression with everyone that he meets. We are extremely lucky to have him and we're so proud of him."

"John Joseph loves his sports, like football and boxing. He will watch them all day long if I let him. He even joined a special needs football club."

"Scarlett loves to find helicopters in the sky, animals, and jigsaws. She's extremely sensory seeking and is a pocket rocket – on the go from 4am most mornings through until bedtime!"

"Emma loves music of all kinds and has gained much pleasure listening to her brother who is a fine classical pianist. She particularly likes him to play the many nursery rhymes she has always enjoyed."

How long can I expect my child/adult to live?

Most people with Dravet Syndrome have a good life expectancy. The oldest adult known to have a Dravet diagnosis in the UK is currently in his 70s. It's likely that there are many more adults living with Dravet Syndrome. But, as a diagnosis was much more difficult to get even 10 years ago than it is today, we simply don't know how many older people are living undiagnosed with the condition.

It's important to be aware that children with Dravet Syndrome are sadly at increased risk of premature death from 'sudden unexpected death in epilepsy', known as SUDEP, and very prolonged seizures known as 'status epilepticus'. See 'Seizures' on page 19 to find out more, including how to reduce these risks.

Even with the increased risks, children with Dravet Syndrome have an 85% likelihood to survive into adulthood. Once reaching adulthood, the frequency of seizures often seems to decrease, as does the risk of premature death.

What will their life be like?

People with Dravet Syndrome may experience significant disabilities but can live long, happy and fulfilled lives. It's likely to be a different kind of life to what you might have imagined for them.

"Dravet Syndrome is a rollercoaster, but the children and adults with Dravet show you a different way to look at life and their smiles and determination makes everything worthwhile."

Mum to a six-year-old with Dravet Syndrome

"As parents, we experience many feelings and emotions. There is fear, sadness, guilt, anger and the unfairness of the whole situation that we, as a family, find ourselves in. Now our son is older, seizures are less of a bother and the main issue is his behaviour and the fact he is getting big and not so easy to take care of... It still isn't easy at times, but we can manage and have started to enjoy life our way, with some adaptations. We found that once we accepted that this is the way our lives are, we were able to move forward."

Dad to a 12-year-old with Dravet Syndrome

> It has certainly not been easy for my daughter, or in fact for us, living with Dravet for more than 40 years. But throughout her life, there has been much happiness too. It still gives us a warm feeling to see the big smile she gives us each night before going to sleep.

Mum to an adult with Dravet Syndrome

> There is a kind of grief associated with the discovery that your child will never live independently. It took some time to come to terms with this. Meeting other families with Dravet helped enormously, as did finding a safe and appropriate environment for our son at a special-needs school. Now he has a place where he belongs and enjoys going. Anyone who spent a day with this child would leave with no doubt that, other than the daily seizures, he lives a blissful and fulfilled life, and long may that last.

Mum to a teenager with Dravet Syndrome

> It has taken a long time to stop watching friends' children progress while our daughter was miles behind, and watching the life I thought we would have. Now six years into our Dravet journey, we've learnt to live life to the max as much as we can. There have been many occasions that I didn't think we would be able to get through living with Dravet. But since we accepted our new normal, it's been a much better path to be on.

Mum to a seven-year-old with Dravet Syndrome

6. What kind of help or support is available?

Children and adults with Dravet Syndrome have complex needs and most require significant levels of care throughout their lives. Some families will need practical support, both inside and outside the home. It's important that you don't feel you need to cope by yourself. Help is available, although it's not always as easy to access as we would like.

Your local authority has a legal responsibility to support families with disabled children and adults, including those living with Dravet Syndrome. (Local authorities or councils are the local government organisation responsible for providing public services and facilities in a particular area).

This support is provided through departments such as social services, sometimes known as '**children with disabilities teams**', '**adults with disabilities teams**' or '**social care services**'.

The local authority also has a responsibility to offer an **Education, Health and Care plan (known as an EHC plan or EHCP)** to children and young people with special educational needs (SEN) (see page 79). This includes those who have learning difficulties or intellectual disabilities which mean that their needs are not fully met by mainstream schools or colleges.

An EHCP applies in England. In Northern Ireland, the equivalent document is called a '**Statement of Special Educational Needs**'.

In Scotland, it's a '**Co-ordinated Support Plan**' and in Wales it's an '**Individual Development Plan (IDP)**'.

In addition to educational support, an EHC plan or equivalent should encompass all the child's needs, such as physiotherapy, speech and language therapy, occupational therapy and other support which can be provided via special schools. An EHC plan can also give parents and young people more choice about which school, or other setting, the child or young person can attend.

Asking for and getting support from local authorities can be a difficult part of a family's Dravet Syndrome journey. Seeking advice and getting the right support in place are really positive steps to take for your family, ultimately improving quality of life for everyone – your child/adult with Dravet Syndrome, their siblings and parents/carers. So, there should be no sense of stigma or guilt attached to seeking this support.

Accessing the right levels of support is not always straightforward, and how easy it is can vary between local authority areas. So, it's never too early to start this process. In Part 4 of this guide, we set out in more detail, advice and guidance on accessing support for healthcare, social and educational needs. We also provide information on getting financial support and assistance for caring for children and adults with complex needs.

Don't forget, if you do face challenges in securing the support you need, Dravet Syndrome UK is here to provide practical support. Get in touch: **info@dravet.org.uk**

Transitioning to adulthood

The transition from child to adult services, when a young person with Dravet Syndrome reaches the age of 16 and beyond, can be an unsettling process for many families. It involves significant changes in the way care for your child is organised, touching on all aspects of life with Dravet Syndrome – including medical and social care, education, finance and legal rights.

You can find out more about navigating these challenges in Part 4 of this guide.

Dravet Syndrome UK also has a *Transition Guide*, which you can download from our website. For a link, see the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

7. Is there a cure for Dravet Syndrome?

There's currently no cure for Dravet Syndrome. It is, however, an exciting and hopeful time, with much ongoing research into new medicines and treatments. This includes genetic or gene-based therapies, which seek to 'fix' the faulty gene that is the underlying cause of Dravet Syndrome.

Just a few years ago we could only hope that one day there would be a treatment that could address the underlying causes of Dravet Syndrome. Thanks to advances in genetic research, we're much closer to this becoming a reality.

Genetic and gene-based therapies have been successful in treating the underlying causes of other genetic conditions (for example, spinal muscular atrophy), so we have good reason to be optimistic.

For the latest information, visit the *Family Guide* resources page: **www.dravet.org.uk/family-guide-resources**

"We tried all the available medications before eventually finding a combination that helped to control our son's seizures, for which we are incredibly grateful. We have close contact with his epilepsy nurse who checks his weight every six months and adapts dosage accordingly."

Mum to a six-year-old with Dravet Syndrome

8. How effective are current treatments for Dravet Syndrome?

Until more new therapies and medicines become available, treating Dravet Syndrome remains highly challenging.

Unfortunately, in terms of seizures, Dravet Syndrome is one of the most treatment-resistant epilepsies. Comprehensive testing and a range of support are needed for the multiple challenges that individuals with Dravet Syndrome and their families face. Because Dravet is changeable and unpredictable, the optimum combination of treatments varies from person to person. (See 'Treatments' on page 43 for more information).

In recent years, there has been some progress in treating seizures with the availability of new medicines, such as Epidyolex (cannabidiol) and Fintepla (fenfluramine). While these medicines may not be suitable for everyone with Dravet Syndrome, and responses to the treatment vary, it's encouraging that more options are, slowly, becoming available to help improve seizure control.

Recognising and treating comorbidities associated with Dravet Syndrome can also be challenging. While improved seizure control can often lead to improvements in comorbidities, this is not always the case. Depending on the comorbidity involved, there are different therapies and approaches available. (See 'Comorbidities' on page 29 for more information).

Ultimately, working with your medical team and other professionals to find the best treatment, therapy and educational plan for your child or adult is the best way to achieve a good quality of life.

The aim of this *Family Guide* is to help you take those next steps – and many more beyond.

PART 2

CHARACTERISTICS OF DRAVET SYNDROME

1. Seizures: types, triggers and what to expect

Seizures are a defining characteristic of Dravet Syndrome. They usually start in the first year of life and unfortunately remain part of this life-long condition, rarely disappearing completely. However, some people with Dravet Syndrome can experience periods of better seizure control, including being seizure-free.

This section provides an overview of the seizures associated with Dravet Syndrome, including possible triggers and types or patterns of seizures.

What is a seizure?

Seizures are sudden bursts of electrical activity in the brain that temporarily affect how it works. Seizures can affect people in different ways, depending on which part of the brain is involved. Some seizures cause the body to jerk and shake, while others cause problems like loss of awareness or unusual sensations.

Seizure glossary: a brief guide to key terms

Seizure classifications

Seizures are classified into three major types, depending on the part of the brain they affect:

- **Focal onset seizures** (previously called partial seizures) start on one side of the brain
- **Generalised onset seizures** affect both sides of the brain simultaneously
- **Unknown onset seizures** is a term used if the location in the brain where the seizure starts is not known

Seizures may also be classified based on their cause (for example, febrile seizures) and/or their symptoms (for example, myoclonic seizures).

An electroencephalogram (EEG) test or scan is a recording of electrical activity in the brain. The brain constantly produces tiny electrical signals. During an EEG test, small sensors are placed on the head to pick up the electrical signals from inside the brain, which are then recorded on the EEG machine. The results of an EEG can help doctors to make correct diagnoses, identify seizure types and decide on the best treatment.

Phases of seizures

You may hear the following terms used to describe the different phases of seizures:

- **'Ictal'** means that a seizure is taking place
- **'Postictal'** means after a seizure
- **'Interictal'** means between seizures

Types of seizures

There are many different types of seizures associated with Dravet Syndrome. Patterns of seizures change and evolve with age. For ease of reference, we've listed these alphabetically here and there's more information on page 21 about when these are likely to happen.

Here is a summary of some common seizure types:

- **Absences** (sometimes described as **'petit mal'**). These types of seizures are usually brief, lasting up to 30 seconds at most. During a typical absence, the person becomes blank and unresponsive for a few seconds. They may appear to be 'daydreaming'. These seizures may not be noticed because they are brief. They may be accompanied by head nodding or jerks. Sometimes absences are called **'atypical'** and this refers to the EEG pattern recorded at the time of the seizure.
- **Atonic seizures** (or **'drop attack'**). In this type of seizure, the person's muscles suddenly relax and they become floppy. If they are standing, they can fall (often forwards) and may injure the front of their head or face. Like tonic seizures, atonic seizures tend to be brief and happen without warning. With both tonic and atonic seizures people usually recover quickly, apart from possible injuries.
- **Clonic seizures** are characterised by jerky movements in which the person's muscles stiffen and relax. These most commonly occur in babies and may last from a few seconds to one minute. Clonic seizures can start in one part of the brain (**focal clonic**) or affect both sides of the brain (**generalised clonic**).
- **Febrile seizures** (sometimes called **'febrile convulsions'**) are usually 'generalised' seizures, triggered by a high or rapidly rising temperature, often due to illness.
- **Focal aware seizures** (previously called **'simple partial seizures'**). In this type of seizure, the person is conscious (aware and alert) and will usually know that something is happening and may remember the seizure afterwards.
- **Focal impaired awareness seizures** (previously called **'complex partial seizures'**) usually involve loss of awareness, and are often associated with extra movements, such as smacking of the lips, fumbling or fiddling movements of the hands. After the seizure, the person may be confused for a while. This is sometimes called **postictal** confusion. It may be hard to tell when the seizure has ended. The person might be tired and want to rest. These seizures are usually longer than absences, typically lasting more than 30 seconds with a further period of time to recover fully.
- **Hemiclonic seizures**. Only one side of the body convulses with this type of seizure.
- **Myoclonic seizures** ('myo' meaning muscle, and 'clonus' meaning jerk) may involve one part of the body or the whole body. They may be subtle or mild or may cause a fall. Myoclonic seizures are brief but can happen in clusters (many happening close together in time). They often happen shortly after waking. Myoclonic seizures are classified as generalised seizures.
- **'Status epilepticus'** (or **'status seizures'**) describes either an individual seizure that lasts longer than five minutes, or a **cluster** of seizures that occur close together without recovery time in-between. There are two types of status epilepticus – **convulsive** and **non-convulsive**:
  - **Convulsive status epilepticus** usually occurs from a **prolonged** tonic-clonic seizure. These seizures can be life-threatening and typically require emergency intervention to stop them, either at home or in a hospital setting (see page 49 for more information on emergency medications and protocols).
  - **Non-convulsive status epilepticus** (sometimes described as **'obtundation status'**) occurs when there is continuous seizure activity but no major convulsive movements (uncontrollable muscle contractions), although there may be subtle twitching or head nods. It is characterised by an altered mental state and the person behaves differently to how they normally do. These seizures are harder to recognise because the symptoms are more subtle. An EEG may be needed to confirm their diagnosis.
- **Tonic seizures.** In this type of seizure, the person's muscles suddenly become stiff. If they are standing, they can fall (often backwards) and may injure the back of their head. Tonic seizures tend to be very brief and happen without warning, and people usually recover quickly, apart from possible injuries.
- **Tonic-clonic seizures** (sometimes described as '**grand mal**') are a combination of symptoms from tonic and clonic seizures. The tonic phase of the convulsion begins first with the person's body suddenly becoming stiff, followed by the clonic phase in which their body jerks rhythmically. These seizures typically last one to three minutes. Toward the end of the seizure, the jerky movements slow to a stop and the person's body relaxes. During this time, they may lose control of their bladder or bowels. Tonic-clonic seizures usually are **generalised onset**, but also can be **focal onset**.

Other common terms:

- **Prolonged seizures** – seizures that last more than five minutes and sometimes over half an hour (or even longer)
- **Recurrent or cluster seizures** – seizures that occur close together without time for recovery in-between
- **Nocturnal seizures** – seizures that occur at night

What triggers a seizure in Dravet Syndrome?

The very first seizure in Dravet Syndrome is often triggered by fever, either from an illness that causes a high temperature or from a childhood vaccination. 'Febrile seizures' (sometimes also described as 'febrile convulsions') are common in infancy (affecting around one in 20 children, usually between the age of six months and three years). In most cases, febrile seizures do not lead to epilepsy, which is why Dravet Syndrome is often 'missed' when the first seizure occurs.

In Dravet Syndrome, a first seizure triggered by fever can differ from 'ordinary' febrile seizures. For example, they are often prolonged (lasting more than five minutes) and may occur in infants younger than six months.

The underlying cause of Dravet Syndrome is genetic, so avoiding triggers for fever (such as vaccination) does not prevent or delay Dravet Syndrome. Early diagnosis and treatment offers the best chance of improving seizures and the other aspects of the condition.

Of course, fever is not only a common trigger for the first seizure. Fever, infections, the start of an illness, or vaccinations, remain common triggers for seizures throughout life (although with time, your child/adult may become less sensitive to these).

Other common triggers for seizures include:

- **Temperature change, both hot and cold:** Warm baths, warm weather, or exertion are common seizure triggers, as are cold weather and things like getting into a cold swimming pool. It's a good idea to be aware of the environmental temperature and take care with any activity that may change your child's/adult's core temperature too quickly. Never leave them alone in a bath or paddling pool, irrespective of the temperature.
- **Teething:** Teething is often associated with an increase in body temperature, which may be a trigger for seizures in some younger children with Dravet Syndrome.

- **Sensitivity to light and patterns:** Seizures may be provoked by flashing lights or other light-related triggers or sometimes, as children get a little older, by particular patterns. This can be as simple as light flickering while travelling in the car. This is often referred to as 'photosensitivity and pattern sensitivity'.
- **Changes to medication:** Adding new medications and withdrawing from previous ones can be tricky, so this process will need to be monitored carefully.

  As your child grows in height and weight, or if their weight changes as an adult, this can also affect how their medication works. At these times, it is worth checking with your medical team to make sure their medication is still at the correct ratio for their weight and height, and make adjustments if needed.

  Not taking prescribed seizure medication or taking it in a way other than what is recommended can trigger seizures. When you collect your child's/adult's prescribed medicines, double check that the medication and strength is correct (don't assume the pharmacy will do this).

  People with Dravet Syndrome or other epilepsies are particularly sensitive to changes in medication. For this reason, in the UK, the NHS recommends that people with epilepsy continue to get the same version of their epilepsy medicine, wherever possible. If a brand name is written on the prescription, pharmacists have to provide that brand.

  Make sure the same brand of medication has been prescribed every time, unless there is a reason for changing, and that your pharmacy doesn't swap to a generic version.
- **Emotional stress or excitement:** This can trigger seizures in some children/adults, as can lack of sleep or excessive tiredness. While it's important to be mindful of this and to be extra vigilant at these times, it's also important to encourage your child/adult to take part in activities for their, and your family's, overall wellbeing.
- **Puberty and menstruation:** The onset of puberty may trigger a change in seizures. Monthly periods may also affect seizures.

This is not an exhaustive list of seizure triggers for Dravet Syndrome, as these can vary from person to person. On many occasions, there may not be an obvious trigger. Seizure patterns do change over time and the same is true for triggers. Nevertheless, you may notice that certain factors or events are likely to trigger a seizure in your child/adult. While these are difficult to fully predict, an awareness of triggers can help with managing seizures in everyday life.

Children and adults with Dravet Syndrome typically need constant care and supervision, as well as help in avoiding seizure triggers. Make a list of any of your child's/adult's known seizure triggers and share these with anyone else who may be involved in their care – for example their nursery, school, day centre, hospice team or carers.

Keeping a seizure diary is one way to keep a track of triggers and other seizure-related information. Seizure diaries can be very helpful for understanding and monitoring seizure patterns. It's also useful for your medical team to see a possible connection between seizures and medications.

If you do keep a seizure diary, remember it's there to help you – not to add to your to-do list. You can use a simple diary or notebook and fill it in by hand, or an app or online diary. Remember, you don't need to record every detail. Often, parents/carers will document major seizures, including how long they last, and whether rescue medication was needed, but will not attempt to record every small seizure.

Making a video recording of a particular seizure, especially if it is one you haven't seen before, can be very helpful. You can share this with your medical team, and any teachers or other professionals who look after your child/adult, to help them understand how their typical seizures present.

How seizures might change over time

Initial seizures

A seizure in an otherwise healthy baby is one of the first signs of Dravet Syndrome. This is usually accompanied by a normal **interictal EEG**, a recording of electrical activity in the brain taken between seizures (see the glossary of seizures on page 19). In Dravet Syndrome, the first seizures typically occur between three and nine months of age, with an average of six months old. Rare cases can happen as early as one month of age, or as late as 20 months.

Typically, this first seizure is generalised **tonic-clonic**, **focal clonic** or **hemiclonic** and in just over half of cases is **febrile**.

Other typical characteristics of early seizures include **prolonged seizures** and **recurrent** or **cluster seizures** that occur close together without time for recovery in-between. Both are common in Dravet Syndrome, especially in the early years. They usually require emergency medical intervention to provide rescue medication and reduce the risks of **status epilepticus**. 'Rescue medication' is the term used to describe medicine given in an emergency situation to relieve symptoms quickly. In these situations, hospital admission may also be required.

All children and adults with Dravet Syndrome should have home rescue medication and an emergency protocol, which includes instructions for administering rescue medication. The protocol needs to be developed with their neurologist. (See 'Emergency medication and protocols' on page 49 for more information).

Where possible, record the time a seizure starts, so you know when to give emergency medication. It also helps you keep track of the length of seizures, as this is useful information to pass to your emergency services teams.

Sometimes it can be difficult to tell if a seizure is over. Two easy ways to check are pinching an ear lobe or gently blowing onto their face to see if they react or blink.

Seizures in early childhood

Between the ages of one and five years old, seizures typically become more frequent and persistent. Additional seizure types can occur including: **myoclonic, focal impaired awareness**, **tonic-clonic**, **atypical absence**, **atonic** and **non-convulsive status epilepticus**. These seizures may happen with or without a fever, and at any time of the day and night. In addition, **tonic** and **tonic-clonic** seizures may occur in sleep and in clusters. An **interictal EEG** may remain normal or (usually after two years of age) start to demonstrate an abnormal EEG background activity.

For definitions of types of seizures, see the glossary on page 19.

Generally, as children get older, typically around four years of age, status seizures begin to settle. However, people with Dravet Syndrome remain prone to status seizures, particularly when they are ill or have an infection.

Seizures may become more frequent around the time status seizures begin to settle. So, someone with Dravet Syndrome may have more seizures but they may last a shorter time and not always require emergency medication.

Another change is that children may begin to experience their seizures at night ('nocturnal seizures'), particularly as they transition through nightly sleep phases. For some families, this feels like a positive change, as your child is less likely to sustain injuries from falling, but for others, it may cause additional anxieties and fears.

"Looking back on his younger years, my son had it hard – endless hospital stays, always really ill in the winter months, having hundreds of absences every day. Now he may have the odd few in a day. He is easier to look after now. I never completely relax, but I do know I'm not on red alert mode all the time now.

As he has got older and is eating better and has built better immunity, and adjusted meds, his seizure activity has definitely reduced. Now he can have four or five months of freedom from seizures. Another achievement of the past three years is that he can be in a paddling pool where the water is not that warm, and he can stay in water for hours. This is new ground for us because cold water was one of his seizure triggers… The most freedom he has had from seizures has been 10 months."

Mum to a teenager with Dravet Syndrome

Protective headgear can be helpful if you need to protect your child or adult from injury during seizures. Protective headgear can be prescribed on the NHS, or you can buy these privately. Ask your occupational therapist, epilepsy nurse or neurologist for recommendations.

Later childhood and teenage years

As children grow older, the seizure pattern may change further. Overall, seizure frequency is high in the first decade of the patient's life, including **myoclonic**, **atypical absence**, and **focal impaired awareness**. Prolonged seizures may continue to be a risk and may still be more likely to happen when a child/adult is ill or has a fever.

See 'Sleep problems' on page 38 for more information, including tips on managing night-time seizures.

"As our daughter became older, the number of seizures she suffered decreased, and the prolonged seizures became less frequent. Puberty was a tough time with her seizures increasing again from the age of 13 but they were still not as severe as they were during those first six or seven years."

Mum to an adult with Dravet Syndrome

Adulthood

Seizure types often change in adulthood and may become less frequent. However, the majority of adults with Dravet Syndrome still experience regular seizures (particularly generalised **tonic-clonic** seizures), and these often occur during sleep. Sensitivity to increased body temperature and fever continue, but the impact of these triggers on seizure frequency and severity is generally milder than in infancy.

When adults have seizures, the injuries they experience can be more severe. Injuries are a part of Dravet Syndrome and can be really upsetting for families of people of all ages. The most common types of injuries are cuts, bruises and burns but more serious injuries can occur. If the head is injured during a fall, look out for signs of concussion and seek medical advice if needed.

Overall, we need more research into seizures in adults with Dravet Syndrome. There's still much we don't know about the changing patterns of seizures in adulthood, partly because Dravet Syndrome is under-diagnosed in adults. What we do know is that improving seizure control has benefits at any age. As newer treatments become available, we hope that they improve life for adults, as well as children.

Sudden unexpected death in epilepsy

Sadly, the risk of sudden unexpected death in epilepsy (SUDEP) in Dravet Syndrome is much higher than in other epilepsies that start in childhood and is responsible for around half of all Dravet-related deaths. The reasons for SUDEP are not clearly understood. As SUDEP is thought to happen either during or following a seizure, it is possible that it is due to a problem with the person's heart or breathing, during or following the seizure.

There are some ways to help to reduce the risk of SUDEP:

- Medical teams can find it hard to talk about the risk of SUDEP. Sometimes, as several families have told us, SUDEP isn't discussed at all. Regularly discussing SUDEP with your medical team is important in working towards finding the best treatment and seizure control plan for your child/adult with Dravet Syndrome.
- Before your next appointment, make a list of questions. For example, you might want to ask: What are the risks of SUDEP for my child/adult with Dravet Syndrome? What are the options for working together to reduce these risks? What can we do to reduce the risks through medication? What could we do through diet or other treatment strategies?
- For more information about SUDEP, including leaflets and downloads that can be shared with healthcare professionals, please visit the **SUDEP Action** website: **sudep.org**

Free seizure monitors

Using a seizure monitoring device cannot prevent SUDEP. However, they can help give you peace of mind by providing an early alert to when seizures are occurring. Different types of devices are available, including cameras that can monitor people from another room in the house, mattress monitors that alert you to unusual movements, or a 'sats' monitor that detects changes in heart rate and oxygen levels.

At Dravet Syndrome UK, we provide free monitors to support families living with Dravet Syndrome. **Visit the 'Seizure Monitor Fund' section of the *Family Guide* resources page of our website**.

"Our son, who is 11 now, has been connected to my hip since his first seizure at seven months old and his diagnosis of Dravet at aged five. I always have eyes on him and he can't be in a room without me for fear of a seizure I won't hear or see. Dravet Syndrome UK provided a video monitor, which enables us to allow him some independence in our home and give his big sister some one-on-one time, while still having eyes on him. I can't tell you all how much this will improve our family's quality of life. I can't explain what this means to us but I have a weight lifted off my shoulders."

Mum to an 11-year-old with Dravet Syndrome

2. Intellectual disability: definitions, causes and what to expect

Intellectual disability (also referred to as 'learning disability') is a term used when there are limits to a child's or adult's ability to learn at an expected level and function in daily life. This includes someone's cognitive functioning (problem-solving, judgement and reasoning) and adaptive functioning, which refers to communicating and daily activities such as washing, dressing, making friends and managing money.

Intellectual disability can cause a child to develop and learn more slowly or differently to a typically developing child. As a child grows older, they may be slower to gain new skills, such as language, or may not develop those skills at all. No two people are the same.

You may sometimes see or hear the term 'developmental delay' used about intellectual disability in Dravet Syndrome. Strictly speaking, the term 'developmental delay' is reserved for describing children under five, while 'intellectual disability' or 'learning disability' are used for older children and adults.

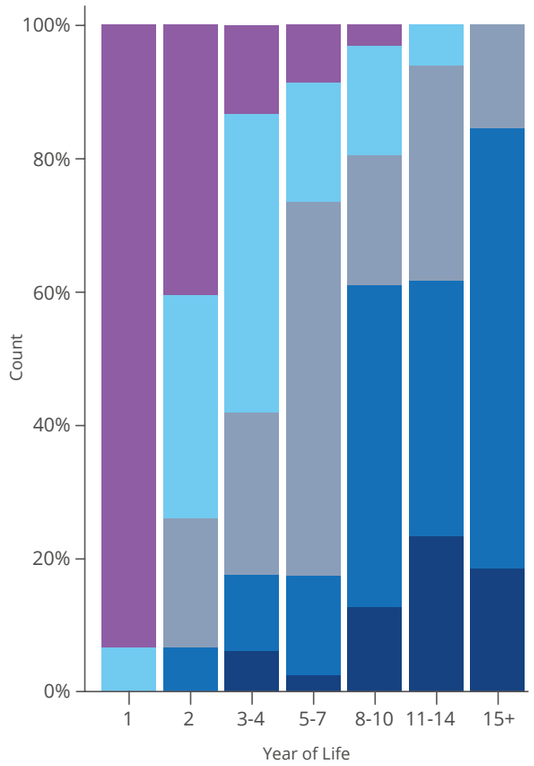
The spectrum of intellectual disability

Everyone with Dravet Syndrome has some degree of intellectual disability. As with other features of the condition, there's a spectrum.

There are different types of intellectual disability, which can be mild, moderate, severe or profound. You may also hear the term 'profound and multiple learning disability' which can also apply to some people with Dravet Syndrome.

The chart below, taken from a 2012 study observing more than 200 UK-based children with Dravet Syndrome, shows how intellectual disability becomes evident during early childhood.

Cross-sectional analysis of developmental status over time



Reference: Brunklaus A, et al. Brain 2012;135:2329–36.

In Dravet Syndrome, someone's intellectual development appears typical in the first year of life and when seizures first start. Over time, usually by two to three years old, a developmental delay becomes noticeable. As childhood progresses, development generally continues to be impaired – some early skills and abilities may be lost, and the comparative gaps with neurotypical peers will continue to widen.

Many children with Dravet Syndrome do make slow but regular developmental progress into their early teens. Nevertheless, by the time they reach adulthood, around 80% live with moderate to severe intellectual disability. It's rare that any adults with Dravet Syndrome will be able to live independently. They will require full-time care and support for life.

Will my child need to attend a special educational needs school?

Whether a child needs to go to a special educational needs (SEN) school or a mainstream school will depend on their individual needs. It will also depend on what their parents/carers prefer. For those with severe or profound intellectual disability, a specialist placement is likely. For those with mild to moderate intellectual disability, other factors may also play a role in the decision. For example whether they have 'comorbidities', such as autism or challenging behaviour, how frequent and severe their seizures are, and if their medical needs can be met in mainstream education. (See page 79 for more on school and education).

What causes intellectual disability in Dravet Syndrome?

It used to be thought that the intellectual disability in children/adults with Dravet Syndrome was caused by epileptic activity. Now, it's widely recognised that the cause is more complex. It's thought that it results from the interaction between the underlying genetic cause of the condition (which impairs the development of psychomotor skills – such as movement, coordination and dexterity – and abilities), seizures, and the effects of anti-seizure drugs.

Long-term use of a class of anti-seizure drugs known as sodium-channel blockers, for example, carbamazepine and lamotrigine, can affect intellectual development. Sodium-channel blockers are not used in Dravet Syndrome, partly for this reason.

Coming to terms with intellectual disability

Accepting that your child has an intellectual disability can be one of the most difficult aspects of a family's Dravet journey. Sadly, at the time of writing, there are no treatments available to improve cognition in Dravet Syndrome. (Cognition is 'the mental action or process of acquiring knowledge and understanding through thought, experience, and the senses'). However, therapies, such as speech and language and occupational therapy, can be helpful in developing a person's 'adaptive skills' (such as washing, dressing, making friends, managing money, and other skills needed in daily life). One of the key benefits of attending a SEN school is that staff often provide these therapies as part of the school day, with the aim of maximising adaptive skills.

Seeking advice early and getting the right support in place can make a huge difference to improving the quality of life for your child/adult with Dravet Syndrome and all the family. Part 4 of this guide talks about what support is available and how to access it (see page 54). This section also gives advice on family wellbeing and coping with the mental health impact of a Dravet Syndrome diagnosis (see page 55).

"Everyone's coping mechanisms are different, but for me, it really helped when I accepted our son would never catch up developmentally. I could then look at him and see all the gifts he does have, rather than see what he couldn't do compared to his peers. He is non-verbal but can make himself understood. Often he knows instinctively who to approach to get what he wants.

He's incredibly empathetic and warms to others who are like him. He doesn't learn the things you want him to learn, but if he's interested in learning something else, he keeps going and trying until he has nailed it. I model myself on my son these days, he uses his energy a lot smarter than I do."

Mum to a six-year-old with Dravet Syndrome

3. Comorbidities: additional conditions commonly associated with Dravet Syndrome

Epilepsy and intellectual disability are the main challenges for children and adults with Dravet Syndrome. However, they also have a number of other associated neurodevelopmental conditions or health problems, known as 'comorbidities'. Some comorbidities are more common than others, and how severe they are varies for each person.

Comorbidities aren't always noticed straightaway. This can be because, early on, health professionals, and parents or carers, will usually focus on managing seizures. Some symptoms won't appear until later in childhood – such as mobility issues.

As with seizures and intellectual disability, once a comorbidity is diagnosed, in most cases, it's lifelong. There are some exceptions, such as challenging behaviour.

Here are the most common comorbidities in Dravet Syndrome.

Autism spectrum disorder

Autism spectrum disorder (ASD) affects how a person communicates with and relates to other people and how they make sense of the world around them. It's not unusual for people with Dravet Syndrome to also be diagnosed with ASD. More than half of people with Dravet Syndrome report some characteristics of ASD.

This association between ASD and Dravet Syndrome is most likely because the two conditions have underlying genes or brain

functions in common, such as an imbalance between signals in the brain. ASD and Dravet Syndrome are both spectrum conditions. This means symptoms will vary considerably and children and adults with Dravet Syndrome will not necessarily have all the features typically associated with ASD.

Characteristics that people with a diagnosis of ASD may experience include:

- Difficulties with social communication and social interaction
- Repetitive and restrictive behaviour
- Over- or under-sensitivity to light, sound, taste or touch
- Highly focused interests or hobbies
- Extreme anxiety
- Meltdowns and shutdowns

If your child/adult with Dravet Syndrome is showing characteristics of ASD, we recommend asking for a referral to a specialist autism team. Getting a formal diagnosis can take some time, but is worth doing as it helps you to access support around managing behaviour, schooling, and other services for children with autism.

For more information on ASD, visit the National Autistic Society website at: **www.autism.org.uk**

“Our son has autistic spectrum disorder (ASD) to some degree. He copes well with structure, sameness and repetitive behaviours. We do encourage normalisation, which can sometimes be challenging. He is very affectionate and quite gentle in nature. He loves hugs and giving hugs and can charm the birds from the trees.”

Dad to a teenager with Dravet Syndrome

Challenging behaviour

Challenging behaviour is the term we use to talk about behaviours which some people with a severe intellectual disability may display when their needs aren't being met. Challenging behaviour is very common in people of all ages with Dravet Syndrome. It can often be difficult to manage and, as children get older, can become more of a disruption to daily family life than dealing with seizures. In a small number of cases, challenging behaviour can include aggression, self-injury, withdrawal, and disruptive or destructive behaviour. Coping with this aspect of the condition can be very difficult for parents/carers and may have an impact on the quality of life of all the family.

It's important to address challenging behaviour and not feel that it's something you just have to live with. There's never any need to feel embarrassed about challenging behaviour. It can happen because a child/adult doesn't understand a situation, for example, due to language difficulties or environment. Or challenging behaviour can be a way of communicating or because someone is in pain. It's not bad parenting.

The term 'challenging behaviour' is not a 'diagnosis' in the same way as other comorbidities, like ASD. However, it's still important to raise this with your medical team. If your child/adult shows signs of challenging behaviour, the first step should be to talk with your medical team to identify the specific behaviour issue, and put a plan in place to manage it. Some aspects of challenging behaviour can be improved with access to appropriate treatment.

For more information on challenging behaviours, visit the **Challenging Behaviours Foundation** website at: **www.challengingbehaviour.org.uk**

As well as managing the challenging behaviour itself, it's important to make sure you and your family have some time out for rest and recuperation. Part 4 of this guide talks about the different forms of respite care or short breaks available and how to access these (see page 84).

Attention deficit hyperactivity disorder

Symptoms associated with attention deficit hyperactivity disorder (ADHD) are common in Dravet Syndrome, and affect up to two-thirds of people with the condition. Children/adults with ADHD may be hyperactive, impulsive and have trouble focusing. They may understand what is expected of them but struggle to complete a task because they cannot sit still, pay attention, or focus on details. Everyone acts like this sometimes but with ADHD these symptoms are there more often. They affect the way someone functions socially, in education and at home.

The positive news is that the symptoms of ADHD can be managed. A diagnosis of ADHD means you can access treatment for this condition, which could include medical and behavioural support. ADHD is typically not diagnosed before six years old but, at any age, you can ask your GP, paediatrician or neurologist for a referral to a specialist assessor with training and expertise in diagnosing ADHD. Who you're referred to depends on your child's age and what's available in your local area. There's no simple test to determine whether someone has ADHD, but your specialist can make an accurate diagnosis after a detailed assessment.

If you think your child/adult is showing signs of ADHD, don't leave it too long before seeking support. There's often a waiting list for assessments.

For tips and advice on living with ADHD, visit the **ADHD Foundation** website at: **www.adhdfoundation.org.uk**

Language and communication

Problems with language and communication are common in Dravet Syndrome, although, like all comorbidities discussed here, the symptoms and how severe they are varies. These difficulties can also be related to other comorbidities, including intellectual disability and autism spectrum disorder.

People with Dravet Syndrome can have difficulties in all, or just some, areas of language development. For example, some people's language may be in keeping with their developmental age, others may only communicate using a few words or be non-verbal. Some people can communicate using sentences but struggle with using language socially, particularly if they also have autism spectrum disorder.

Speech and language therapists (SALTs) assess all aspects of language and communication. They provide guidance and support to help people to understand and communicate to the best of their ability. They advise parents, carers and teachers about modifying the environment, which includes simplifying language and using pictures to help with understanding.

SALTs can also advise on alternative forms of communication that may benefit your child/adult including:

- **The Picture Exchange Communication System®**, or PECS®, allows people to communicate using pictures. It's a way for people with little or no communication to share their wants and needs with parents, carers, teachers and peers.

- **Makaton**, or 'key word signing', is a simple form of communication where manual signs are used alongside speech. It also has a set of symbols.

- **An augmentative and alternative communication (AAC) device**, is a tablet or laptop that helps someone with a speech or language impairment to communicate. The term AAC device is often used interchangeably with terms like speech-generating device (SGD) or assistive communication device.

While it's never too late to benefit from speech and language therapy, we recommend seeking specialist support as early as possible. SALTs can start working with parents and children to develop language skills from around two to three years old. If your child has eating and drinking difficulties, they may already be involved in their care. If your child attends a SEN school, then language and communication are also a central part of the curriculum.

Speech and language therapy is also available for adults with Dravet Syndrome, to assess and manage speech, language, communication, and/or swallowing disorders. It's usually provided through learning disability services.

Any health professional can refer you for speech and language therapy, such as your GP or neurologist. However, in most areas of the UK you can also 'self-refer' by contacting your local service directly. You can find an independent (private) speech and language therapist through the **Association of Speech and Language Therapists in Independent Practice (ASLTIP)** website: **www.helpwithtalking.com**

"Our daughter could talk until the age of two but then she lost the ability to speak. Although it eventually came back, when she lost her ability to speak, she learned Makaton (sign language) and this really helped. As an adult, she still loves learning sign language and uses it alongside speech to communicate with friends."

Mum to an adult with Dravet Syndrome

Movement and mobility

Our brain controls every movement we take. In Dravet Syndrome, the part of the brain that helps to control electrical messages (the sodium ion channel) doesn't function as it should. That's why up to 80% of those with Dravet Syndrome report having difficulties with movement and mobility.

People with Dravet Syndrome may develop problems with coordination (known as 'ataxia') and a variety of difficulties with walking (known as 'gait' issues). Generally, children with Dravet Syndrome start walking at the usual age of 8-18 months, but then develop movement and mobility issues as they get older. Typically, there's a deterioration of someone's walking ability after the age of 10. As a result, many people with Dravet Syndrome become increasingly dependent on their parents/carers to move around and do daily activities.

Gait alterations

People with Dravet Syndrome have a variety of 'gait alterations', which means differences in the way they walk.

Crouch gait is the most common gait alteration, affecting around half of people with Dravet Syndrome. It's characterised by the upward bending of the ankles, and bent knees and hips.

Parkinsonian gait involves an unsteady walking posture caused by changes in posture, slowness of movement and a shortened stride. It's often seen in people with Parkinson's disease.

Cerebellar gait is a wide, unsteady gait, common in people with 'cerebellar ataxia', a disorder that occurs when the area of the brain responsible for controlling gait and muscle coordination becomes inflamed or damaged.

There are things you can do to try and manage and maintain someone's mobility. This includes: specifically designed footwear called orthotics; muscle strengthening exercises; and generally keeping as active as possible, for example, through regular exercise such as swimming. An occupational therapist can advise on useful adaptations that you could make at home to help with home-based exercise and maintaining mobility, such as adding rails along the wall.

To maintain your child's/adult's mobility, it can be helpful to get a tailored physiotherapy programme to follow. Also, simple things, like walking on different surfaces (for example, pebbles or sand), climbing up and down steps and bending and stretching, can be extremely useful for helping to build strength. Swimming and hydrotherapy can be beneficial too.

For people with Dravet Syndrome, mobility and movement difficulties are life-long. Starting therapies as early as possible can help to avoid these difficulties getting worse. Speak to your medical team for advice and for referrals to:

- A physiotherapist
- An occupational therapist
- An orthotics clinic
- A specialist gait clinic

If your child attends a SEN school, the school may also be able to help with referrals to relevant specialists. Exercises and activities to support mobility needs are likely to be integrated into the school day.

Wheelchair support

As they get older, many children with Dravet Syndrome need wheelchair support. This is because as well as mobility difficulties, they can also become tired easily when they have had seizures. Some families find that once their child outgrows a pram or a buggy, they still need assistance getting around. In these cases, having a wheelchair can make a positive difference to family life.

Finding a suitable wheelchair is not always easy. Depending on where you live in the UK, there may be NHS or local authority support available to help you buy or adapt one. It may also depend on the type of wheelchair needed.

The Dravet Syndrome UK private online forum (see page 57) is a great place to find up-to-date advice directly from other families on wheelchairs and other mobility aids.

The Dravet Syndrome UK 16+ Assistance Fund is a non-means tested grant of up to £1,000 per year that can be used to improve the wellbeing of adults with Dravet Syndrome. It may be helpful for improving or upgrading a wheelchair, or helping to customise your living arrangements to be more wheelchair friendly.

For more information, see the 'Apply for grants' section and the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

Growth, digestion and 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.

Sleep problems

Sleep difficulties affect between 75% and 97% of people with Dravet Syndrome. This is far greater than families with young children in the general population and with other epilepsies – only 30% of these report sleep problems. Daytime sleepiness may also affect children/adults with Dravet Syndrome.

We don't know the exact reason for poor sleep in Dravet Syndrome – many possible factors may contribute. What is clear is that sleep problems can have a major negative impact on the quality of life of both children and adults with Dravet Syndrome and their families. Lack of sleep can exacerbate behaviour problems, affect a child's abilities to learn and provoke seizures. For parents and carers, lack of sleep and sleep disturbance can also have a huge impact on their ability to manage everyday life.

If you're the parent or carer of someone with Dravet Syndrome, it's very important that you make healthy sleep a priority for you too. We know that can be easier said than done.

We sometimes hear from families that some healthcare professionals refer to Dravet-related sleep issues as 'normal toddler sleeping issues' or 'just one of those things' but this is not the case. Sleep problems are not easy to address in Dravet Syndrome but they are part of what makes living with this condition difficult for all the family.

If you need support in clarifying the role of sleep problems in Dravet Syndrome to health or social care professionals, contact us at: **info@dravet.org.uk**

Coping with night-time seizures

Night-time (nocturnal) seizures are one of the main factors affecting the sleep of children/adults with Dravet Syndrome.

Here are some sleep management tips to help cope with night-time seizures.

- **Get a specialist bed**. These have high sides to make sure your child/adult can't fall out and injure themselves. An occupational therapist should be able to advise on and provide specialist beds.
- **Sleep with your child in a double bed, or have a single bed in the bedroom for a parent/carer to use** when your child/adult is unwell due to seizures.
- **Explore respite options**, for example your child/adult with Dravet Syndrome could stay in respite care, such as a hospice, where there are night staff, or you could use a 'waking nights' service in your own home. To request a needs assessment, contact your social worker, if you have one, or your local authority. (For more information see 'Social services and your rights' on page 68 and 'Respite care or short breaks' on page 84).
- **Set up monitoring systems** that can alert you when your child/adult is having a seizure. By providing an early alert to seizures, monitors help enable prompt emergency treatment. Children and adults with Dravet Syndrome need 24/7 supervision, and seizure monitors can be a helpful tool for supporting this. But it's important to note that seizure monitors are an assistive device only. You will still need to look for signs of a seizure. There are lots of different monitors available. In our experience, the following types of devices are the most helpful:
  - **Pulse oximeter machines** that monitor a person's heart rate and oxygen levels. Typically, when someone has a seizure their heart rate increases and their oxygen levels drop. If they are being monitored on a pulse oximeter machine during a seizure, the monitor may sound an alarm so that parents/carers can administer emergency treatment if necessary. The pulse oximeter is attached to the patient by a sticky probe, generally on the toe.
  - **Epilepsy mattress monitors** which alert to tonic-clonic seizures (see page 19 for definitions of seizures) and can be set up to sound an 'out of bed' alarm to let you know if the person has got up.
  - **Good quality video monitors** or CCTV that allow parents/carers to keep a watch over their sleeping child/adult, without needing to be in the same room.

Dravet Syndrome UK provides free monitors to support families living with Dravet Syndrome. For information, visit the 'Seizure Monitor Fund' section on the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

Supplements to help with sleep

Melatonin, often referred to as the sleep hormone, is a central part of the body's sleep-wake cycle. It can be given as a supplement to help with settling into sleep. **Chloral hydrate**, a sedative, is another sleep-promoting medication that your doctor might recommend. Like most medicines, these treatments may work for some but not everyone. Ask your medical team for more information.

The charity **Cerebra** has information and advice on managing sleep problems, specifically aimed at children with brain conditions. This includes a sleep guide you can download.

For links to more information, visit the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

Infection and immune problems

Frequent ear, nose, throat, lung and digestive infections can be a problem for some people with Dravet Syndrome. How to manage these infections should be part of your discussions about care with the local epilepsy nurse specialist and paediatrician or child neurologist. Paracetamol or ibuprofen may be offered to keep the temperature down, but there's no guarantee this will prevent fever-induced seizures.

Dysautonomia

Dysautonomia is the term given to problems with autonomic body functions, like your heartbeat, breathing and digestion. The autonomic nervous system regulates certain body processes, such as blood pressure and the rate of breathing. This system works automatically (autonomously), without a person's conscious effort.

The term dysautonomia covers a range of issues, including problems with temperature change, decreased sweating, fast heart rate (called 'tachycardia'), low blood pressure, fainting and dizziness, and sluggish digestion and blood circulation.

If you think your child/adult with Dravet Syndrome might be experiencing these symptoms, it's important to let your epilepsy nurse or doctor know. It might be necessary to perform an electrocardiogram (ECG) which measures a person's heart rate, looking for any change in heart rhythm. Additional investigations, or a referral to a cardiologist (heart specialist) might be needed, depending on what the initial tests show.

PART 3

MANAGING DRAVET SYNDROME

1. Treatments: medications and additional therapies

This is an exciting and hopeful time for Dravet Syndrome, with much ongoing research into new medicines and treatments. As treatments improve, along with understanding of the condition, researchers expect that long-term outcomes for people with Dravet Syndrome will improve.

Medications

Children and adults with Dravet Syndrome typically need a combination of medications, known as anti-seizure medications (ASMs), to help control or reduce seizures. To keep someone free from seizures is the ultimate goal of these medications. However, good seizure control in Dravet Syndrome is rare. At the time of writing this guide, very few children/adults live seizure-free.

Because Dravet Syndrome is a spectrum condition, not all children/adults respond in the same way to treatments. Treatments and treatment combinations are given on a trial-and-error basis to see which works best. What 'good seizure control' looks like, may vary from person to person.

For a summary of medications that your medical team might prescribe, visit our website: **www.dravet.org.uk/medications**

Managing medication is part of daily life with Dravet Syndrome. Make sure you always have plenty of the medicines and equipment, such as syringes, that you need.

Administering medication

As with all medications, it's very important to comply with all the instructions you are provided with when you administer medications for Dravet Syndrome, particularly the dose and making sure that the course is finished as directed. People with Dravet Syndrome can be very susceptible to the slightest change, so it's essential that you consult with a medical professional before making any changes to medication.

We suggest you speak to your child's/adult's neurologist if you have any concerns over their medication. (See 'Taking a proactive role with your medical team' on page 47).

Important: Medications that should NOT be used with Dravet Syndrome

Sodium channel blockers are 'contraindicated' for people with Dravet Syndrome, which means they **should not be used**. This is because they may increase or prolong seizures, and with long-term use, may have an adverse impact on intellectual development.

Medicines that should be avoided include: **carbamazepine, lamotrigine** and **phenytoin** (although phenytoin can increase seizures if used as a daily maintenance medication, it can be useful when used intravenously as an emergency treatment).

Fever control

As a fever often triggers a seizure, good fever management is key. Keep a close eye on your child/adult and get to know the signs and triggers of a seizure. For example, it's useful to know their 'normal' baseline temperature so you can intervene quickly if this starts rising.

Sometimes, children/adults may be prescribed extra anti-seizure medication, such as clobazam, during a febrile illness. Paracetamol and ibuprofen are also sometimes given to help manage fever. Finding the right fever control treatment for your child or adult is something that must be discussed with your medical team.

Rectal fever management

If your child/adult is in the middle of a seizure, has just had one, or can't take oral medication for other reasons (for example, they are unwell, vomiting, have a stomach bug, or are reluctant to take them), you can use rectal paracetamol or ibuprofen suppositories. These can be prescribed by your GP and are handy to have at home. As with all medications, seek advice from your GP before using any new medication and never exceed the dose prescribed.

Don't try to manage fever both orally and rectally at the same time. It should always be one or the other.

Generic versus branded medications

Generic names are the names given to the main ingredient of the medication (for example, sodium valproate). Branded names are those given by the drug company making the medication (for example, Epilim) and refer to specific formulations made by a particular company.

The important thing to remember is that you should stick with the brand that was initially prescribed, assuming it's working for your child/adult. There's a chance that a different version of their epilepsy medicine would have a different effect.

The National Institute for Health and Care Excellence (NICE) recommends that people with epilepsy continue to get the same version of their epilepsy medicine wherever possible. If the person who prescribes your child's/adult's epilepsy medicine wants to change the version you receive, they should discuss this with you first.

Ketogenic diet

The ketogenic diet is a medically prescribed diet for children and adults with drug-resistant epilepsy, including Dravet Syndrome. All types of ketogenic diet have restricted carbohydrates and are high in fat. Protein is always included – the amount depends on which version you're using.

There are four different types of ketogenic dietary therapy available. Each diet is tailored to individual needs. As with any other medical treatment, you shouldn't try the ketogenic diet without first discussing it with a medical professional. The diet needs to be monitored by a dietician and a child neurologist who have experience in ketogenic dietary therapies.

Blood tests are required every few months when someone is on the diet. You should fill out weekly reports for your dietician, especially at the start of the diet to make sure that adequate ketone levels are being achieved (ketones are a type of chemical that your liver produces when it breaks down fats).

The diet should be started with no other changes to treatment being made. Usually, it's possible to tell within three months whether a diet is helping or not. If the diet is beneficial, it's usually recommended that the person stays on it for two years before slowly being weaned off. In most cases, the benefits of the diet remain even after being weaned off, and people can go on to a normal diet.

Matthew's Friends is a charity specialising in all types of ketogenic dietary therapy. For more information visit their website at: **www.matthewsfriends.org**

"When our daughter was eight years old, we hit a rough patch. Her seizures started to get a lot more frequent and worse. No matter how much the doctors upped the meds it made no difference. We reached the top dose of everything. One option offered by her doctors was the ketogenic diet. It wasn't easy. In fact, her seizures got worse for a while, but what I saw was a much brighter, engaging and talkative little girl, it was amazing. Gradually, over some months, the diet started to help with her seizures, so much so we managed to wean her off one treatment and lower other meds. She remained on the ketogenic diet for four years before being weaned off."

Mum to a teenager with Dravet Syndrome

Vagus nerve stimulation

In vagus nerve stimulation (VNS), a device is surgically implanted into the chest, like a pacemaker. The vagus nerve runs from the base of the brain to the chest and abdomen, with one branch running on each side of the body. A wire from the VNS device is wrapped around the left vagus nerve. When activated, the device sends an electrical signal from the vagus nerve to the brain. Stimulation by the VNS device is thought to help regulate signalling in the brain, so it reduces the overactive signalling that causes seizures in Dravet Syndrome.

The VNS device is programmed to deliver electrical stimulation to the vagus nerve at various times and with various intensities. The stimulation usually begins at a low level and is increased based on symptoms and effectiveness. Parents/carers can activate the VNS device if they sense the start of a seizure.

VNS therapy may be a helpful option for some, but not everyone with Dravet Syndrome responds to this form of treatment. Research suggests that around half of those undergoing VNS therapy show at least a 50% reduction in seizures as a result.

"Our daughter had her first seizure when she was just seven weeks old. From then on, her childhood was spent in and out of hospital until she had her VNS treatment at the age of eight, after which her seizures reduced in frequency and duration."

Mum to an adult with Dravet Syndrome

“We tried various anti-epileptic drugs in various combinations but none worked. Then, just before our son turned six, he had a VNS device implanted. The impact of the VNS therapy has been life-changing. We were well-informed that it wouldn’t be a cure but it has dramatically reduced the frequency and severity of his seizures. He’s calmer, his progress academically and socially has accelerated – and it has improved life for us as a family.”

Mum to a nine-year-old with Dravet Syndrome

Additional therapies

Many additional therapies are available locally on the NHS. Some parents/carers choose to supplement NHS care with private therapy, especially if a particular alternative therapy is not available on the NHS. To be referred for additional therapies speak to your GP, consultant or epilepsy nurse, or other healthcare professionals involved in your child’s/adult’s care. In most areas of the UK, you can also ‘self-refer’, which means you can contact your local service directly.

Additional therapies include:

- **Occupational therapy:** Paediatric occupational therapists help children develop skills around self-care, school and play. They will assess whether your child has functional difficulties, for example with sensory and motor skills, and help them overcome these. They might also help your child learn to use the toilet and exert bladder control. They will work closely with your family to enable your child to discover just how much they can do for themselves to achieve maximum independence.

Occupational therapy also benefits adults with Dravet Syndrome. It can help with techniques to improve fine motor skills including writing and buttoning clothes. An occupational therapist can offer advice on how to create a safe environment – for example, by providing protective helmets or pads to minimise injury during seizures, or home adaptations such as stair rails and bathroom handles to help with mobility and getting around the house. Your GP or consultant can refer you to an occupational therapist.

- **Speech and language therapy:** Speech and language therapists (SALTs) can assess and treat your child’s/adult’s speech, language and communication to enable them to communicate to the best of their ability. They can also support people with eating, drinking and swallowing problems and advise on alternative forms of communication that may benefit your child/adult.

- **Physiotherapy:** Physiotherapy can help your child/adult to be as independent as possible. It can also prevent and minimise complications that can develop. For example, your child’s/adult’s mobility might reduce after a seizure or as gait difficulties progress, so physiotherapy is often ongoing. Your GP or consultant can refer you.

- **Social/play therapy:** Guided play therapy helps children learn and make sense of their world or come to terms with difficult issues and emotions. This can include one-to-one activities or group play with other children. Your local authority might employ play therapists. Find out what services are available locally and ensure your GP or main health contact refers you to these.

For more information, visit the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

It can sometimes feel as if your life is one big therapy appointment. But accessing therapies can be a great benefit to your child/adult. Starting therapies as early as possible can be key in maintaining or improving skills and abilities.

“My son attends weekly equine therapy which has been an amazing experience for him to take part in. It really brings a huge smile to his face, and he loves trotting on the horse.”

Mum to a teenager with Dravet Syndrome

Taking a proactive role with your medical team

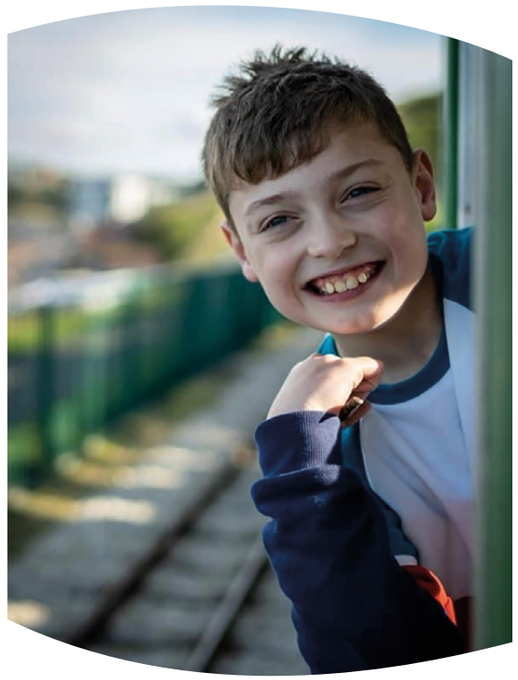
You know your child/adult better than anyone, so it’s important to monitor and report any positive and negative effects which may be associated with their medication or other therapies. Medicating someone with Dravet Syndrome can be tricky to get right. It will vary from person to person, and as your child grows and changes.

Don’t be afraid to take an active role and discuss all questions, suggestions and concerns with your medical team, as it is likely you will be in the driving seat of your child’s/adult’s care. Do some research – the Dravet Syndrome UK website is a good place to start – and develop a list of any questions you have so you go prepared for all meetings.

You have the right to ask for a referral for a second opinion

If, for any reason, you're not happy with the care that your child/adult is receiving, you have the right to ask for a second opinion. This may be to another neurologist or different type of hospital, for example, a specialist centre with expertise in Dravet Syndrome. Asking for a referral can feel awkward but don't be put off.

If you're having difficulties in getting a referral, try speaking to the NHS Patient Advice and Liaison Service (PALS) in your local hospital if you're in England or Wales. In Scotland this is the Patient Advice & Support Service (PASS) and in Northern Ireland the Patient and Client Council (PCC).



> **"We have become battle hardened over the years. Unfortunately, things don't come easy when you have a child with additional needs. My advice is to believe in yourself, don't be fobbed off. Seek independent advice and shout LOUDLY! Also remember that where your child is concerned, you are the expert!"**
>
> Dad to a teenager with Dravet Syndrome

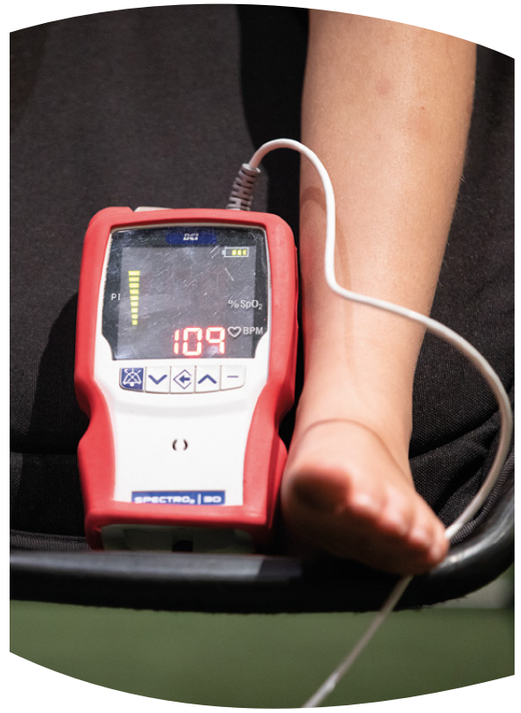
Striving for the best care for adults

Adult neurology services are sometimes less knowledgeable about Dravet Syndrome than children's services. Adults, as well as children with Dravet Syndrome, should have regular reviews, on at least an annual basis. If this is not happening, then do follow-up and request that more regular reviews take place. If you have been discharged, you have the right to go back to your GP and ask for a referral.

Although seizure control may improve for many adults, it's never too late to stop striving for the best combination of treatments. Trying new medications as an adult can still make a big difference to seizure control and overall quality of life.

> **"From around the age of 19, our son's seizure pattern fluctuated but he still continued to have tonic-clonic seizures regularly, sometimes still needing rescue medication. As the years have gone by, his seizures are better controlled, and he appears more settled."**
>
> Dad to an adult with Dravet Syndrome

2. Emergency medication and protocols



Emergency protocols

As Dravet Syndrome is a rare condition, it would be unrealistic to expect all medical professionals to immediately recognise it and know how it should be treated. Having emergency protocols that are readily available and accessible can make treating your child/adult in an emergency situation a lot easier for everyone concerned. Emergency protocols will also make sure that the same procedures are followed, wherever you are.

It's important to work proactively with your medical team to produce some protocols. We recommend preparing three emergency protocols:

- **Emergency seizure protocol:** Detailing the medications to be used when the person is seizing, the order in which to use them, and the appropriate doses in milligrams per kilogram (mg/kg).
- **Ambulance protocol:** Detailing the medications which can be used on the way to the hospital and information about the measures needed to be taken when you get there. You will need to work with your local consultant to write the protocol and they will liaise with your local ambulance service.
- **General hospital protocol:** There will be times when you just know that something is not right with your child/adult, yet you can't quite put your finger on it. A general hospital protocol would provide some brief information on Dravet Syndrome, any other diagnoses your child/adult has, and what tests should be carried out, for example, blood tests, swabs, checking ears and throat.

All protocols should include your child's/adult's information – their date of birth, address, current medications, allergies and contact numbers for your medical team. They should be on hospital letter headed paper and signed off by your consultant. You may find it helpful to have a laminated version of your child's emergency protocols and an electronic copy of each plan on your phone.

Once you have your protocols, we advise you to keep a copy in the following places:

- Your child's/adult's bag at all times
- At their school/college/home
- With your ambulance station
- In the A&E department and on the ward of your local hospital
- At your GP surgery

Communication passports

A ‘communication passport’ provides a practical, person-centred approach to passing on key information about a person with complex communication difficulties. It’s not a replacement for emergency protocol information, it should go alongside it. The passport is a useful tool for hospital staff to help them get to know a person with communication difficulties and interact with them. It can help the hospital staff to make sure your child/adult understands the situation they are in. A communication passport presents the person with communication difficulties positively, as an individual, not as a set of ‘problems’ or disabilities.

For more information, visit the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

The practicalities of using emergency (rescue) medications

Rescue medication is the term used to describe medicine given in an emergency situation to relieve symptoms quickly. In epilepsy, if a seizure lasts more than five minutes, rescue medication is usually required.

Unfortunately, prolonged and ‘cluster’ seizures (where seizures occur close together without recovery time in-between) are all too common in Dravet Syndrome, particularly in early childhood. All children and adults with Dravet Syndrome will need to have an emergency protocol that has been developed with their neurologist, which includes details of their home rescue medication and instructions for administering it.

It’s important to note that rescue medication varies from person to person. For some, oxygen is used at home, especially if there is ‘respiratory depression’ with seizures, which means the lungs fail to exchange carbon dioxide and oxygen efficiently. But this varies on a case-by-case basis and should always be discussed with your medical team.

For a list of emergency medications, see the Dravet Syndrome UK website: **www.dravet.org.uk/medications**

It doesn’t matter how many times you have to administer a rescue medication, it can still be a scary experience. Over time, parents/carers get used to having to do it, but the fears and anxieties never go away. It’s a stressful situation – you may find that as well as administering the medication, you’re dialling 999 and trying to calm others around you.

Take a deep breath and try to remain as calm as possible. What you’re doing for your child/adult is amazing and potentially life-saving. Many parents/carers say that at the time of administering the medication they remain calm, it’s afterwards when their child/adult has come round that the panic and upset sets in. This is completely normal and is the body’s way of coping in times of stress.

Initial emergency treatment once in hospital

- The medical team will want to check your child’s/adult’s basic airway, breathing and circulation, and are likely to set up an intravenous line (called a cannula), give oxygen and call other members of the team to help, depending on how unwell they are. They may take blood to check blood glucose levels and for infection, and to ensure that the kidneys and liver are working well.

- The first rescue medication given in hospital is usually an intravenous benzodiazepine, typically lorazepam, which can usually be repeated once.

- Your child’s/adult’s emergency protocol may indicate that they respond best to a particular emergency treatment and for this to be given, if possible, as the next step.

- In the past, intravenous phenytoin would be given as the next step. In current practice, intravenous levetiracetam is generally preferred. However, intravenous phenytoin can still be beneficial in some cases and may be given even if the person is already on regular levetiracetam.

- If there’s any delay in inserting a cannula to administer intravenous medication, then diazepam or paraldehyde may be given rectally so it can get into the body quickly.

- In some extreme cases, when veins cannot be accessed by cannula, a procedure called Intraosseous Infusion (IO) is used. IO involves injecting medications, fluids, or blood products directly into the marrow of a bone. It can be very scary to witness but is an important, potentially life-saving procedure that enables vital medications and fluids to be quickly delivered directly into the vascular system when it's not possible to use other methods.

- If your child/adult doesn't respond to the initial intravenous medication, then an anaesthetist should be called, as further medication and the ongoing seizure may reduce the drive to breathe, meaning that help with breathing may be needed.

Ventilation

People may need ventilation if they have a condition that makes it hard for them to breathe properly or when they can't breathe on their own – for example if they are unconscious.

A medical ventilator is a machine that helps a person's lungs to work by pushing air in and out of their lungs so their body can get the oxygen it needs. They may wear a fitted mask to get oxygen from the ventilator into their lungs. Or, if the condition is more serious, a breathing tube may be inserted down the throat to supply the oxygen to the lungs.

Why ventilate?

There are two main reasons why your child/adult may need to be ventilated – either because they are unable to breathe effectively for themselves, or because they are unconscious and so can't protect their airway as they would usually.

The first reason is most commonly due to infections, either in the lungs or somewhere else in the body, something obstructing their airway, or tiredness. Problems with breathing can also be caused by some chronic conditions.

The second reason, when they are unable to protect their own airway, is normally due to fluctuating or very low consciousness levels. This typically happens when a person is seizing or following a seizure. An unconscious person is in danger because there is a risk of their stomach contents entering their lungs, by inhaling vomit, which can cause an obstruction or infection. When someone is unconscious, it can result in them not being able to breathe effectively and take in the oxygen they need for their cells and tissues to function.

What happens when someone is ventilated?

If your child/adult is ventilated, they will be given some medication to help them relax, even if they appear unconscious. An 'endotracheal' tube will be put in their mouth and fed down the windpipe ('trachea'). This is called intubation. The tube is then connected to a ventilator, sometimes called a life support machine.

The machine then assists, or takes over, your child's/adult's breathing until they are well enough to breathe by themselves. It will take anything from a couple of hours to a few days, or occasionally, weeks. There are several different ways of using these machines. Each person will need something different. But all the machines deliver oxygen into the lungs and take carbon dioxide away.

During this time, your child/adult will be monitored extremely closely, particularly their heart rate and oxygen levels. They will be given sedation to make sure they are comfortable and sleepy.

Will I be consulted if my child/ adult needs ventilation?

For children: If your child needs ventilation, a doctor and an anaesthetist will try and discuss the pros and cons with you before they proceed. But in the case of emergencies, they may have to explain the procedure afterwards. It's up to the doctors and nurses whether you're able to be there during the intubation, but they will keep you fully informed. This is a difficult time as your child will be in an intensive care unit with several tubes and wires around them.

If you don't have a paediatric intensive care unit in your local hospital, your child will need to be transferred to the nearest centre.

For adults: The process is slightly different for adults, where the medical staff will take what's known as a 'best interest decision'. As a parent/carer, you will be consulted, but it's ultimately the medical professional who has the final say on what will happen medically, or indeed in relation to any major decision affecting your adult son's or daughter's life. This can come as a shock if you're not prepared.

PART 4

LIVING WITH DRAVET SYNDROME

1. Family wellbeing and coping strategies

Having a family member with Dravet Syndrome affects the entire family and can have a huge impact on many areas of life that most families take for granted.

Here, we provide you with some tips and ideas on how families can cope with the ups and downs of living with a Dravet Syndrome diagnosis. Hopefully this will help you realise that you're not alone on your journey.

Emotional wellbeing

Being the parent or carer of someone with Dravet Syndrome can have a huge impact on emotional wellbeing. Adjusting to living with Dravet Syndrome is not easy. It's a different kind of family life, bringing with it a host of challenges and rewards that most families might not anticipate or expect.

> "Being the parent or carer of a child with Dravet Syndrome is at times like living in the centre of a whirlwind. You have things thrown at you from all directions, often unexpectedly, while at the same time, you're trying to keep two feet firmly on the ground and acting like everything is ABSOLUTELY FINE! Over the years, we have found that once you can get support in place with regards to help at home and overnight respite, our lives have settled down somewhat and you get into a routine."

Dad to a 12-year-old with Dravet Syndrome

There's a grieving process involved in coming to terms with the fact that your child has Dravet Syndrome. To feel sadness, loss, guilt or anxiety is completely normal. You're not alone. A recent study showed that over 90% of parents/carers reported feelings of depression, anxiety, and stress at some points in their lives.

> "I used to be a planner. Planning was very important to me, having things organised and things to look forward to. With Dravet, I've had to learn to let this go. You can't plan in the same way. You can have an idea of what you might be doing, but things are always subject to change. This can be really disappointing for siblings, and tough for us as parents too."

Mum to a teenager with Dravet Syndrome

> "My journey has been one that follows the stages of grief: denial that there was an issue and isolation of myself through not communicating feelings and believing I needed to be strong; anger at the medical profession; depression at various stages; and finally, acceptance. I love my little boy. I would change everything if I could, but I am happy that I have come out of it a stronger and better person, with great pre- and post-Dravet friends and family."

Dad to a teenager with Dravet Syndrome

“We learned to live with Dravet Syndrome and to not live in fear. I wanted us to have a normal life, but I didn’t want to live in fear and stop him from living his life. And he absolutely loves his little life now. If the worst was to happen, I would want to be able to look back on his life and remember the good things and not regret a single thing or to have stopped him doing the things he loves. I know his triggers now and even though some of his triggers are the things he enjoys, I still allow him to do it, just in a moderate way. I remember reading from another family that quality over quantity was their motto, and it just stuck in my head.”

Mum to a six-year-old with Dravet Syndrome

Post-traumatic stress

When a child or adult receives a diagnosis like Dravet Syndrome, it’s a life changing event – one which can have an intense emotional impact on the entire family. While everyone’s experience is unique, it’s common to experience some trauma. And in certain situations, some family members may develop post-traumatic stress disorder (PTSD).

PTSD is well-known but often misunderstood. In fact, there are many myths about PTSD that can prevent people from seeking treatment, such as it only happens to soldiers in war. In fact, any distressing event can trigger PTSD – including having a child or a sibling with a life-changing illness or injury.

Don’t underestimate the value of talking with a professional. A therapist trained in trauma can use evidence-based treatments, such as talking therapy, cognitive behavioural therapy (CBT), or possibly medication, to help you reframe and cope with the thoughts and emotions causing anxiety, depression, or other PTSD symptoms. The most important thing to remember is that we’re all human, and we all struggle sometimes. The key thing is to give yourself, and others, time and space. Be kind to yourself and ask for help when you need it.

“Before we had a genetic test, I started to flit around the internet to see what I could find. I found Dravet Syndrome and was devastated. I knew this was what our baby daughter had. She ticked all the boxes. Eventually, the results came back positive for a SCN1A mutation. Although this confirmation of what we already suspected was difficult, it also made things a lot easier. With the letter of diagnosis, we were able to join Dravet Syndrome UK (I had looked at their website, time and time again, before the diagnosis) and gain access to a wealth of knowledge and support… Our advice to any recently diagnosed family would be that it’s not all doom and gloom, once you get your head around it. It’s not what we would choose for our children, and you will have your good days and your bad, but they will amaze you every single day.”

Mum to a four-year-old with Dravet Syndrome

There’s no right or wrong way to deal with the emotional impact of living with Dravet Syndrome. It’s a lifelong condition and your need for support may vary at different times in your life. Sometimes we need to surround ourselves in a fully supportive environment, other times we feel more resilient and can work things through ourselves.

What’s important to know is that life does get better and there are numerous coping strategies that will help you overcome challenges and get through the tough times. Of course, we all know that some coping strategies are healthier than others. Three of the most positive coping strategies are:

- Talking about your situation with people that you feel comfortable with
- Making time for yourself, away from your caring responsibilities, even if it’s just for a few hours
- Being prepared to ask for and accept help when you need it

Talking about your situation

Families living with a rare condition like Dravet Syndrome can often feel isolated and distanced from their usual support networks, as friends or even other family members may not quite understand what they are going through or the intensity of the situation. Yet there are individuals and communities out there who will know exactly how you feel.

Support from Dravet Syndrome UK

Dravet Syndrome UK runs a private online forum. It’s a closed discussion forum only accessible to families registered with us. This online community is a ‘safe space’ where parents/carers can discuss the highs and lows of living with Dravet Syndrome. It’s also a great source of practical advice and tips for daily life. Please be reassured that there’s no pressure to be active on this forum. We know it can feel like a big step, so take your time – just know there is a welcoming support network there for you when you’re ready. **If you’d like to join the forum, please email info@dravet.org.uk**.

Our **Family Support Manager** is also here to help. Whether you just want a friendly voice to chat to, need someone to listen while you off-load, or could do with some practical assistance, you can get in touch by calling **01246 912421** or emailing **info@dravet.org.uk**. We’re not able to give medical advice, but we’re here to listen, share from our knowledge and signpost you to other resources and support.

Support from other organisations

Other ways to connect and talk include:

- Meeting up with local families who are also living with Dravet Syndrome
- Joining support groups organised by local charities, such as those specialising in disabilities
- Seeking counselling from professionals
  - In England, you can self-refer to the NHS's Improving Access to Psychological Therapies (IAPT) service for therapy. This includes talking therapies, cognitive behavioural therapy (CBT) and counselling.
  - In Wales, Scotland and Northern Ireland, your GP will need to refer you to access therapy: referral to your Local Primary Mental Health Support Service in Wales, the local NHS board in Scotland, and a regional Health and Social Care Trust in Northern Ireland.
  - You can also access therapies privately, by finding a qualified therapist through the directories of the British Association for Counselling and Psychotherapy (BACP) and the UK Council for Psychotherapy (UKCP).
  - UK-wide, mental health charity **Mind** offers support and information.

You can find website addresses for all these organisations on the *Family Guide* resources page of our website**: www.dravet.org.uk/family-guide-resources**

Making some time for you

Caring for a child or adult with Dravet Syndrome can become all encompassing. It's easy to become so involved, and at times overwhelmed, that you simply forget to make time for yourself – but we can't overstate just how important doing this can be for your health and wellbeing. For example, a trip to the cinema or a meal out once a month, a lunch date with your partner, coffee or a walk with friends can make a huge difference to your personal wellbeing. This, in turn, will impact on how you're able to cope with the caring responsibilities. Of course, there are times when it's just not possible to get out, or perhaps you're just too tired – but it's essential to make some time for you.

"Caring for someone with Dravet Syndrome is FULL ON. For me, running plays an important part in keeping me calm and it's a great way to stay positive. Some may say you are running away. So what?! Run away for 20 minutes. I find that I can leave the house with the weight of the world on my shoulders but by the time I am back in the door my perspective has changed.

We can at times feel isolated and vulnerable. I joined a running club which has led to me finding like-minded people and making great friendships. I also enter races, my favourite distance to train for is the marathon. It gives me a focus over a number of months, something else to think about outside my caring situation. Of course, running isn't for everyone, it could be anything you enjoy. Just getting outside and stepping away from your caring role, even for a short while, can make a huge difference."

Dad to a teenager with Dravet Syndrome

Asking for and/or accepting help when you need it

Accepting help with caring for your child/adult with Dravet Syndrome can be difficult for many reasons. A major challenge is that families are often too worried to accept offers of help from family members, such as grandparents or close friends, in case a seizure occurs.

It's important to find ways to access help that works for you and your family. One option might be to teach family members how to take care of the particular needs of your child/adult with Dravet Syndrome. You could ask your epilepsy nurse if they can provide training sessions for grandparents or uncles and aunts.

Another option is accessing professional respite care. If you don't already access respite care of some description, now is a good time to consider your options. To find out more, see 'Respite care or short breaks' on page 84.

"We learned to lean on others a bit more, and not let the fear of him seizing control us. We are still not super adventurous, but we go on trips now. He loves being outside, so we are out in most weather and we were able to let go enough to have another child."

Mum to a six-year-old with Dravet Syndrome

Relationships

When any child comes along, relationships are bound to change. When you're dealing with seizures and the many other challenges that living with Dravet Syndrome brings, relationships can alter dramatically.

"With our son having seizures day and night, my wife was beside herself with worry. I would like to think that I was supportive, but in the typical male fashion, I bottled up or hid my own feelings for fear of making things worse. I was the man, I had to be strong. But bottling things up increased my isolation. Following confirmation of diagnosis, we joined Dravet Syndrome UK and it really made a huge difference. The online community in the private group is a great source of information, advice and support, and also a place where victories large or small are celebrated. We have been to Dravet Syndrome UK's Family Weekend at Center Parcs three times and made some great friends. The dads' night out held there allowed me to relax with others who know what life is like living with Dravet Syndrome but not to actually discuss the problems – to be normal!"

Dad to a teenager with Dravet Syndrome

Relationships between parents

All of a sudden, you're not just parents, you're caregivers, nurses, teachers and advocates, among many other roles. You may find you and your partner just slip into these roles and agree about the path you want to take when it comes to treatment. However, you may find that you disagree. Perhaps one partner takes longer to come to terms with the diagnosis than the other, or you disagree about medications. Equally, you may find that your relationship becomes stronger.

Try to be as open and honest as you can with one another. Share your fears and feelings as you will probably find you're thinking along the same lines. Some people find talking to a counsellor helpful as a way of sharing how they feel. Speak to your GP or social worker about being referred to a counsellor.

"For us, life has turned out differently to what we expected, but it's not as bad as it might be. In my experience as Mum, I tend to think of the worst-case scenario and anything else is a bonus, while my partner has the glass half-full approach. Life usually ends up somewhere in the middle!"

Mum to an adult with Dravet Syndrome

For guidance on supporting brothers and sisters of children with Dravet Syndrome, see 'Sibling support' on page 64.

Relationships with grandparents

Being a grandparent of a child/adult with Dravet Syndrome can present some very different challenges. Not only are grandparents concerned for their grandchild, they may also worry about how the challenges of living with Dravet Syndrome could impact on their own child.

In some cases there may be little that grandparents can do to help, and they can feel helpless and frustrated, particularly if they do not feel confident enough to look after their grandchild. In other situations, families may become reliant on help from grandparents. Either way, it can be helpful to share feelings and concerns with others in similar situations.

For more information on support for grandparents, contact us at: **info@dravet.org.uk**

"I'm a practical kind of person who doesn't panic under stress, so when my granddaughter's seizures started at four months old, of course I was concerned and worried. But my biggest fears, hurt and worry were for my daughter and her husband. As parents, we had to find new ways of being strong for them so that they could be strong for their baby. This was the first time we were totally unable to help or make things better. I'm pleased to say things are much better these days. Seizures will always be part of our granddaughter's life, and she will need 24-hour care forever, but we've adapted. We've conquered the fears and now concentrate our thoughts on all the good."

Grandmother to an eight-year-old with Dravet Syndrome

Where possible, it can be good to get grandparents involved. Maybe they could accompany you to an appointment to get a better understanding of Dravet Syndrome? Or ask your epilepsy nurse specialist if they would organise a training session.

If they feel uncomfortable looking after their grandchild alone, or you're not confident about this, maybe they could come round to play or spend time with your child while you go upstairs for a bath, or a much-needed nap. This way, if anything happens, you're there. Their confidence will grow and the relationship between your child/adult and their grandparents will also strengthen.

"We live just down the road from my parents and they see a lot of what our life is like, but no one can really know what life is like for us. They help us out where they can and provide a lot of emotional support. It was difficult for them to come to terms with the developmental aspect of our son's diagnosis, but the more time they spend with him, the more they can see his gifts and magic that he brings to everyone he meets."

Mum to a six-year-old with Dravet Syndrome

Relationships with friends

Having a child with Dravet Syndrome can have a big impact on your social life and friendship circle. There are friends who will always be there for you – no matter how many times you cancel arrangements, no matter how often your child demonstrates a challenging behaviour or seizes in their company. Sadly, there may also be some friends who disappear from your life over time, which can feel very upsetting and hurtful.

Changing friendships is not unique to Dravet Syndrome. We all have friends that we lose during our lifetime, as circumstances change and we find we have less in common. Try not to dwell too much on the friends you lose, but celebrate the friends you keep – and the new friends you discover.

> **"I now have two types of friends. There's my 'normal friends', people I've known for many years, who I catch up with and enjoy spending time with. And there's my '3am friends', the people who I can call in a crisis at 3am and they will understand, be there for me and drop everything to help. That type of friendship is invaluable and to be treasured."**
>
> Mum to an eight-year-old with Dravet Syndrome

Work

Having a child with Dravet Syndrome has an enormous impact on the working life and finances of parents/carers. As with all of the topics in this 'Family wellbeing' section, there is no right or wrong approach when it comes to managing working life. Families have to do what's best for them, as well as what's necessary financially. Some families choose for one parent to give up work and stay home; others decide to carry on working either for financial reasons or their own mental wellbeing. It's important to consider your needs as parents/carers, as well as those of your other children and the rest of the family.

If both parents/carers are working, or if you're a single parent who works, try to have good contingency plans in place for care, for those times that the person who usually cares for your child/adult is unavailable.

Emotional challenges of being at work and home

Being at home all day with a child/adult with Dravet Syndrome can be difficult and stressful. Not only are you dealing with seizures but possibly also behavioural issues, isolation or other challenges, as well as looking after the home.

If you have a partner who works, it can become very easy to feel resentful towards them – they get to go out every day, speak with other adults, have an actual lunch break and drink their coffee when it's still hot. Equally, for the partner that works, being the only breadwinner can be stressful. They may feel guilty (even if they don't express this) that they are not sharing the everyday challenges of home life with Dravet Syndrome, and wish they could spend extra time supporting you and your family at home.

For single parents, we recognise the situation can be even more complicated. You can find out more about support and short breaks from caring on page 84. The Dravet Syndrome UK community includes many different types of families, including single parents. Our private online forum is a good place to get in touch with people in a similar situation.

For more information on the forum and other support available, visit the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

Our **Family Support Manager** is also here to help. Whether you just want a friendly voice to chat to, need someone to listen while you off-load, or could do with some practical assistance, call **01246 912421** or email **info@dravet.org.uk**

Exchanging work for full-time care

Deciding to exchange work to be a full-time carer can be a very big life change, particularly if you enjoyed your work. You may find being at home is fulfilling but miss the challenge and responsibility of work and the social interaction. For many people, work defines their sense of who they are – redefining this can feel challenging but also very fulfilling. Leaving work can also have a significant impact on your finances.

If you're considering working but are unsure of whether it's right for your family, you can get information and advice from the charity Carers Trust at: **www.carers.org**. If you do choose to give up work then it will be important to have some structure and routine to your days. Find out about local children's groups or activities for adults. Your social worker should be able to signpost you to appropriate groups where you can meet others, helping to reduce the isolation that can be felt with such a big life change.

> **"When my daughter received her diagnosis, it made my husband and I rethink our priorities. It suddenly became more important to stay at home with her than go out to work. To keep my mind occupied I continued studying for my degree. Money was tight at times, but it was the right decision for us."**
>
> Mum to a 10-year-old with Dravet Syndrome

Holidays

When you're the parent/carer of a child with Dravet Syndrome, holidays can easily become something that you just don't consider. You might be concerned about travelling abroad or that your child may not adapt to change well. You might worry that they may not be well enough to travel, or not feel confident to be too far away from your local hospital and the people who understand and know your child. Holidays are a very personal thing and your family has to do what is right for you.

> **"Now six years into our Dravet journey, we've learnt to live life to the max as much as we can. But for the first three years, we didn't go away anywhere far from where we lived. If we did, we would google the route and the closest A&E, and it would have to be somewhere we were familiar with, which was literally the beach or our home town."**
>
> Mum to a seven-year-old with Dravet Syndrome

We know that not everyone can afford to go on holiday. There are several charities that may be able to help with the cost of the holiday, as well as insurance cover. The **Disability Grants** website provides a helpful list of these organisations.

You can find the link on the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

For more information on holidays, see 'Respite care or short breaks' on page 84.

2. Sibling support

Siblings of those diagnosed with Dravet Syndrome experience many things that you would never wish your child to see: prolonged seizures, ambulance trips, hospital intervention and challenging behaviour, to name just a few.

Siblings also need to adapt to the day-to-day pressures of living with Dravet Syndrome: the fact that there are times when plans are cancelled, holidays are not possible, sleepovers just too intense and that their parents are stressed, worried and exhausted. They may also experience those feelings of isolation or guilt that often go alongside the pressures of living with a disabled sibling.

Despite all these difficulties, many families report how caring and loving siblings can be to their brothers and sisters. Having a sibling with special needs undoubtedly brings challenges, but there's a positive side too. Living with a brother or sister with Dravet Syndrome helps to teach empathy, kindness and compassion. With the right knowledge and support, siblings cope and adapt, and often develop extraordinarily close bonds with their brothers and sisters.

> **"My daughter's seizures are very unpredictable and we have no warning that they're going to happen. We used to plan days out as a family and my other children would get excited. Then she would take ill, and that's quite upsetting for the others. Now we still plan days out but don't tell the children so if she has a seizure it doesn't matter. We find being open and honest about the condition is the best way forward, even if it's difficult to accept at times. Her older brothers are amazing with her."**
>
> Mum to a three-year-old with Dravet Syndrome

> **"Our son, who has Dravet Syndrome, has taught our daughter kindness and empathy as he has taught us all. A while ago someone asked her if she had a magic wand would she cure Dravet? Her reply made us smile. She said she would get rid of the seizures and all the parts that hurt her brother and make him ill, but she wouldn't want to get rid of all of it as it makes him who he is and, unlike her friends' brothers, he still cuddles and kisses her and always will. We couldn't help but agree with her."**
>
> Mum to 10-year-old twins, one of whom has Dravet Syndrome

> **"Having a sibling with Dravet Syndrome is well, different. But I wouldn't change it. We are extremely close in a way that no one else would understand and our bond is unbreakable. Because my sister has certain characteristics, she's very honest and tells me how it is, and to me that's a best friend. Growing up with a sibling with Dravet is hard and pretty scary, but it means she and I are very close."**
>
> Sibling of an adult with Dravet Syndrome

Supporting your other children

As parents/carers, you're already facing a hugely challenging situation. Supporting siblings may seem like too much additional pressure. However, it's important to be aware of the potential impact having a brother or sister with Dravet Syndrome may have on the wellbeing of siblings.

Here are some practical ways in which you can support siblings:

- **Wherever possible, help siblings to be siblings rather than caregivers, especially during childhood.** Inevitably the practicalities of living with Dravet can make this challenging and sometimes impossible. Find ways for them to have fun with their brother or sister. Encourage safe play and other activities that they like doing together. This will strengthen bonds between them and help build positive memories for siblings in the future.
- **Talk honestly to them, at a level appropriate for their age.** Research shows that siblings cope best when they are told about what's happening and share their feelings about it. Of course, it's not always easy to start these conversations. You may find it easier to discuss issues with children by doing activities together. With younger children, you could try making a scrapbook about your family that includes information about family life with Dravet Syndrome. You could read story books together about children who are disabled or have additional needs and their siblings. For copies of storybooks for siblings, please contact us at **info@dravet.org.uk**
- **Give them a chance to ask you questions about things that might be worrying them.** The organisation **Sibs** (**www.sibs.org.uk**) which supports people with a disabled brother or sister, suggests making a question box to put on top of the fridge where siblings can write down any question they have about their brother's or sister's disability or condition. If you're not sure about the answer, let siblings know that you will ask it at the next appointment you have with the practitioner who supports your child.

- **Have a plan in place for younger siblings in case of emergency hospital visits.** When a child with Dravet Syndrome has a seizure that requires an emergency trip to A&E, or an overnight stay in hospital, this can be really hard for siblings. The unpredictability of Dravet Syndrome means it's hard to plan for every emergency. But try to have a plan-of-action in place so that siblings have an accurate understanding of what's happening and what they are expected to do. When the situation is under control again, check in with siblings and ask them how they are feeling.
- **Reassure them that their own life, with school, friends and activities, is important.** Siblings often feel guilty about getting on with things that they enjoy. Let siblings know that it is okay for them to lead their own life and to enjoy having fun with friends. Tell siblings that you want to spend time with them too.
- **Set aside time and attention just for them.** Try to make sure that, as parents/carers, you spend some quality time with siblings, doing things they enjoy. This doesn't always have to be a big trip or day out – even setting aside 10 minutes of one day can make a difference. Another nice idea to let siblings know they have your attention is to write them messages, post-it notes or postcards. Make sure to write something fun and positive, such as "I am thinking about you today" or "Have a fun time at football club".
- **Make the most of respite care opportunities, if they are available to you.** It's not always easy to take time off from caring responsibilities but it's very worthwhile with many benefits for all the family, including siblings. It means you can spend time relaxed together, and gives them a break from the responsibilities and pressures that come with being a sibling. (See 'Respite care and short breaks' on page 84 for more information).

Counselling for siblings

Sometimes, despite all your best efforts, life can feel very difficult for siblings, and the challenges of living with a brother or sister with Dravet Syndrome can have an impact on their mental wellbeing. If you think your child might be struggling, there's additional support available. Counselling can be very beneficial at different stages of a sibling's childhood or as an adult. Ask your GP for a referral.

In addition, joining specialist sibling support groups can be hugely beneficial, helping siblings to understand their feelings, share fears or worries and, importantly, know that they are not alone.

- The organisation **Sibs** (**www.sibs.org.uk**) is a fantastic source of support for siblings of disabled children, and for parents too. They offer information and activities aimed at both younger siblings and siblings who are adults.
- Many local authorities run sibling groups or young carer organisations, where they can get together with other siblings in similar situations. Ask your GP or social worker for more information.
- If your child/adult with Dravet Syndrome attends a hospice, they might also run sibling activities or have play therapists who are able to help siblings organise their thoughts and feelings.

Genetic counselling

You may find that adult or teenage siblings have some concerns about genetic issues, such as whether they might pass on Dravet Syndrome to their own children. This particular worry can be addressed by asking your GP or neurologist about genetic testing, which should be supported by counselling. In around 90% of cases, the gene mutation that causes Dravet Syndrome is 'de novo', meaning that it arises spontaneously and is not inherited or passed on.

Whatever the outcome, genetic counselling is always recommended to provide appropriate support and guidance. To receive genetic counselling, your neurologist or paediatrician will need to refer you to your local **NHS regional genetics centre** or a private provider. More information about genetic counselling, including a list of NHS genetic centres, is available via the NHS website.

You can find a link to the website on the *Family Guide* resources page of our website:
www.dravet.org.uk/family-guide-resources

Dravet Syndrome UK events for siblings

Our **Annual Siblings Awards** recognise the amazing unsung heroes of the Dravet Syndrome community. There are two award categories: 'Super Sibling Awards' for siblings from 5-15 years old, and 'Sibling Recognition Awards' for siblings 16 years old and above.

Our **Annual Weekend Away** includes a special day of fun activities for siblings. It's a great opportunity for siblings to meet others who have a brother or sister with Dravet Syndrome and share similar experiences, with no explanations needed.

Find out more about the awards and weekend away at:
www.dravet.org.uk

"To other siblings who may be in my situation, my advice would be to talk when things get too much, speak to your family. You may feel you shouldn't as your parents have a lot to deal with already but you are also still their baby and they will always have time for you. For me, being a part of Dravet Syndrome UK certainly helped. Receiving the Super Sibling Award when I was younger meant a lot and I have always loved meeting other families at the Annual Weekend Away. I connected with one sibling in particular and although we never really speak about Dravet, there is this mutual understanding and we just get what each other has been through with our siblings."

Sibling of an adult with Dravet Syndrome

3. Social services and your rights

A person with Dravet Syndrome will require a level of support throughout their life. The good news is that you're entitled to help.

In the UK, local authorities (councils) have a legal responsibility to help families with disabled children and adults. As a parent/carer of someone with Dravet Syndrome, you're likely to be entitled to certain social support that can help you, your child/adult and your family. This could include equipment for daily living, home care assistance, access to play schemes, educational provisions, transport assistance, home adaptations, access to respite care and other services.

In addition, the local authorities are expected to work together with the NHS to meet the needs of children, young people and adults living with complex health needs. There are two schemes available – one for children and young people called 'NHS Continuing Care' and one for adults, called 'NHS Continuing Healthcare'. **You can read about NHS Continuing Care for Children and Young People on page 71 and NHS Continuing Healthcare on page 76**.

At Dravet Syndrome UK, we often hear from families who didn't know that they are entitled to support from their local authority, or are reluctant to access it. This can lead to them missing out on a range of helpful resources or struggling unnecessarily without support. We also hear from families who have tried to access support from social services, only to be told that their child or adult with Dravet Syndrome doesn't meet the criteria.

In this section of the *Family Guide*, we cover the areas of support and entitlements available from local authorities and provide advice on challenging decisions.

Depending on where you live in the UK, and the age of your child/adult with Dravet Syndrome, the relevant local authority teams may have slightly different names – such as 'social services', 'social-work department', 'children with disabilities teams' and 'adults with disabilities teams'.

Why accessing social services can benefit your family

There are so many benefits to accessing support from social services. Having a good social care package in place can make the difference between surviving and thriving.

Asking for support from social services can seem daunting at first. There's a formal process to go through, which involves a fair amount of paperwork and face-to-face meetings. Some families might feel there's a stigma in having a social worker, others may find the formal terminology used by social services (for example, 'a child in need') off-putting or alarming. Some may even worry that involving social services means risking their child/adult being taken 'into care'.

> **"It's really vital to have a care package and social care support. With the complexity of the needs that someone with Dravet Syndrome has, coping on your own is not sustainable. My advice is to get a needs assessment and be really honest about how Dravet Syndrome affects all of your family. It can be a battle, but don't accept something if you aren't happy with it. Everything we all go through as parents is worth it if it means that our child gets what they need."**
>
> Dad to a teenager with Dravet Syndrome

Yet once they have a care package in place, parents and carers often tell us that having the support of social services is a huge relief, describing it as a positive or even empowering step.

It's important to know that social services are there to help you and your family. Don't be put off by scare-stories or the myth that asking for help is somehow a sign of failure. Social care is not just about child protection or safeguarding. Social services are there to help people with additional needs have a better quality of life and cope with a complex family life. Just as the NHS has a duty to provide medical care to those who need it, social services have a duty to provide proactive support services to children and adults who meet their eligibility requirements, and those who care for them.

Although the process can be complicated and time-consuming, it's absolutely worth pursuing. There is no doubt that getting a social care package in place that meets your child's/adult's needs, with a social worker who knows and understands your family, can make a huge difference to your wellbeing and resilience in dealing with the everyday challenges of living with Dravet Syndrome.

> **"The only advice I would give to other parents facing this is to be confident. You know your child best, so don't be afraid to speak out. You will have good days and bad, feel on top of the world one day, and the next like your world is falling apart. It's normal and it's okay, you are not alone."**
>
> Mum to a three-year-old with Dravet Syndrome

Asking for a needs assessment

The first step in accessing support from social services is to contact your local council to ask for a 'needs assessment'. Every child and adult has a statutory right to a needs assessment under the Care Act 2014. This is an opportunity for you to tell a professional about the needs of your child/adult with Dravet Syndrome and the family as a whole. Following the assessment, the local authority should draw up a plan that defines what support services are needed.

Although you can ask for an assessment over the phone or in person, it's best to ask in writing so you have a paper trail to follow-up on if needed. You can contact the director of children's services at your local authority to request this. The charity **Cerebra** has some helpful template letters for asking for a needs assessment, with different ones for England, Scotland and Wales.

You can find links to these templates and others on the *Family Guide* resources page of our website:
www.dravet.org.uk/family-guide-resources

You can also ask your GP, health visitor, community nurse, paediatrician or a voluntary organisation to contact social services on your behalf.

We know the needs assessment process isn't always straightforward and some families may be put off applying. For example, you may be told by your council or a healthcare professional that you're unlikely to get support or 'don't meet the threshold' required. However, until a needs assessment has been done, neither the council or any other professional can make this judgement.

Don't take 'no' for an answer. It's your statutory right to insist on a needs assessment. The law says that local authorities must assess every child or adult who is, or may be, 'in need'. Children and adults are 'in need' if they need help with health or development, or if they have a disability. Carers who are the family or friends of disabled children are also entitled to an assessment, either as a separate assessment, or through the disabled child's/adult's assessment.

When can I ask for a needs assessment?

You can ask for a needs assessment at any time. If your child/adult has been newly diagnosed with Dravet Syndrome, don't delay in getting a needs assessment done – the sooner you start putting the support you need in place, the better. But it's never too late. Even if you have previously had a needs assessment, you can ask for a reassessment or review. You do this in the same way that you asked for the first assessment. When services are already being provided, the assessment should be reviewed regularly.

The charity **Contact** has more detailed advice about accessing support services for families of disabled children and **Disability Rights UK** has this information for disabled adults. **Dravet Syndrome UK** is also here to provide support and guidance, for example with writing letters to confirm that a needs assessment should be carried out.

You can find links to these organisations and resources on the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

What to expect at a needs assessment

Preparation

The local authority should provide information about the needs assessment process, such as how it will be carried out and how long it takes. You will also be given information about what services are available. This includes those provided by social services departments and other services in your area, for example, a play scheme or activity group.

Try to set aside some quiet time to review this information. Make a list of any questions you have and any particular services that would be helpful for your family. It's also worth thinking about how to describe everyday life with Dravet Syndrome. Social workers are unlikely to be familiar with Dravet Syndrome and may assume it's a more straightforward form of epilepsy. Be prepared to talk through the different aspects of your child's condition and how it affects everyday life for your family.

The assessment

The assessment will usually take place in your family home. A social worker from your local authority will usually take the lead role, although professionals from other agencies may be involved. They must meet with you and your child, as well as other key people, such as siblings and other close family members. This may involve more than one meeting.

You don't have to do the needs assessment alone. If you're a single parent or your partner can't attend, you're entitled to have a friend, relative or advocate take part with you.

It's important to bear in mind that the assessment should always be 'needs-led' and not 'budget-led'. This means that if needs are identified, the local authority has a statutory obligation to meet these needs and can't simply rule out services based on their available budget.

The aim of the assessment should be to identify your family's needs, so the social worker will ask you for lots of information about your child/adult – from seizure activity, how they sleep, eat and communicate, to relationships with siblings, and more. Don't be alarmed at the level of detail and don't hold back in your response. And if your social worker doesn't ask about an important aspect of family life, tell them about it anyway. The person carrying out the assessment should work in an open way. This means that they listen to your views and share any relevant information with you.

After the assessment

Your local authority has to decide whether it's going to provide support for all, some, or none of the needs that have been identified during the assessment. The local authority may decide there's no need for them to provide you with services. However, they must be transparent and explain to you why they have taken this decision, and share with you any eligibility criteria which they have used in their decision-making. If you disagree, you can challenge it using the local authority's complaints procedure. (See 'Challenging local authority decisions' on page 74).

NHS Continuing Care for Children and Young People

Continuing Care for Children and Young People (called 'Children's Continuing Care' in Scotland) is a way of funding health and care packages for babies, children and young people from birth to 18 years old with complex healthcare needs (as a result of disability, accident or illness). It's applied when their needs cannot be met by existing mainstream or specialist health services. (Please note, this is different from NHS Continuing Healthcare, which is for eligible adults aged 18 years and over. See page 76 for more information).

Continuing Care packages are commissioned to meet the individual needs of each child/young person and their family, across health, education and social care. They are not means-tested.

You can ask any healthcare professional for a referral for a Continuing Care assessment, for example a community nursing team, public health team, local authority or children's social care services, or through a school or education setting.

The process varies slightly between local authorities but is usually co-ordinated by a specialist nurse assessor who will visit you and your child, and obtain reports from the team of health and social care professionals involved in their care. An assessment and a decision should be completed within six weeks of referral. If awarded, your package should be regularly reviewed to ensure it is still meeting relevant needs. The first review takes place within three months of the award and then annually.

Continuing Care is an important option to explore as it can give you access to a comprehensive package of care. The assessment process can be rigorous, but don't let this put you off as there are significant benefits to having a package in place.

As with the needs assessment, take some time to prepare how you will describe the impact of Dravet Syndrome on the everyday life of your child and your family. Don't limit this to seizures; include other aspects of the condition such as intellectual disability, challenging behaviour, autistic spectrum disorder, mobility and sleep issues, or anything else that's relevant to your child's situation.

Don't be tempted to downplay how difficult living with Dravet Syndrome can be. Most people – including many professionals – don't realise just how extensively Dravet Syndrome impacts family life. It's important to be honest, so that you get the levels of help that you need.

Carer's assessment

A needs assessment should take into account the needs of the rest of the family, as well as the child or adult with Dravet Syndrome. However, the aim of a carer's assessment is to give you a chance to tell social services about the things that could make looking after your child/adult easier for you.

A carer's assessment focuses on you as a parent and your needs, your wellbeing, health and safety issues, and important commitments, such as relationships, education and employment. All parent carers have a right to ask for an assessment of their needs at any time. This can be if your needs or commitments have changed, for example, you may wish to take up education, training or employment. You can ask for a carer's assessment by contacting your local authority.

The local authority should consider work, education and leisure opportunities when you're being assessed. Examples of services that you might receive after a carer's assessment include, driving lessons, help with housework and gardening, emotional support and short breaks.

The charity **Cerebra** has some helpful template letters for asking for a carer's assessment, with different letters for England, Scotland and Wales.

You can find links to these templates and others on the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

What does a care plan look like?

Once your local authority agrees that services should be provided to support the care of your child/adult with Dravet Syndrome, they should draw up a care plan that sets out:

- What services will be provided
- How long the services are needed for
- What the local authority plans to achieve by providing the services
- What each person and agency is expected to do
- The date of the next review

The type of services provided will vary according to the needs of each individual family. These might include:

- **Short breaks (respite care) services:** Local authorities now have a duty to provide short break services and make clear how families can access these. These might include support in the home, day-care away from home, overnight short breaks or residential breaks. See our section on 'Respite care or short breaks' on page 84 for more information.
- **Blue Badge disabled parking permits:** If your child/adult has a Blue Badge, it allows you to park close to where you need to go, by using disabled parking spaces. Blue Badge holders can also ask for a disabled parking space near their home. Having a Blue Badge can take a lot of stress out of getting around. The **Contact** website has helpful advice about Blue Badge permits. While the Blue Badge scheme applies throughout the UK, the rules about who qualifies are different in each of the nations. You can find links to more information about this on the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**
- **Play, leisure and recreation:** UK law recognises that disabled children need good quality play and leisure opportunities. This means that local authorities must provide access to play and leisure, and support those who need help to play or special equipment to access certain activities and facilities.
- **Equipment and home adaptations:** In general, social services are responsible for providing equipment for daily living and non-medical needs (while your health authority is responsible for providing equipment to meet nursing or medical needs). You may also be entitled to a grant to cover the costs of any work you need carried out in your home to make it suitable for a disabled child or adult.
- **A personal assistant (PA):** This is someone employed by the family or young disabled person to help with day-to-day living. They can be involved in personal care, as well as many other tasks that you decide need doing, such as help with household chores. You might choose to employ a PA if you receive money from the local authority in the form of 'direct payments' or a 'personal budget' (see box on right).

Your care plan should be reviewed regularly to make sure you're getting the right services for your child/adult and that these are being provided in full. It's important to seek advice if your needs change or your local authority has told you a service is no longer available.

Personal budgets and direct payments

Local authorities might offer you the option of a 'personal' or 'individual' budget. This is also sometimes referred to as 'self-directed support'. It's an allocated amount of money that the local authority considers sufficient to meet all your child's/adult's eligible needs.

If your local authority agrees that your child/adult needs services, you can choose to be given money in the form of '**direct payments**' to buy these services yourself, or they can be organised by the local authority. The advantage of direct payments is that it gives you more control over how your child's/adult's needs are met.

Some examples of how direct payments can be used include:

- Getting help with your child's/adult's personal care, for example bathing, dressing or eating, or help looking after them overnight
- A sitter service to look after your child/adult when you're out
- Help for your child/adult to use leisure facilities
- Help with household tasks to free up your time to look after your child/adult
- A place at a day nursery or after-school care
- Someone to accompany your child/adult on holiday

Challenging local authority decisions

Parents/carers can make a complaint if their local authority has refused a needs assessment or Continuing Care referral, decided that a person is ineligible for support, or if there are problems with the services they are receiving, such as:

- Service quality or appropriateness
- Delays in decision-making or implementation of services
- How services are delivered (or not delivered), including the way complaints are dealt with
- The amount of help given, how frequently a service is provided, any changes made to services or how much you're asked to pay
- The attitude or behaviour of staff
- How eligibility and assessment criteria are applied
- A local authority policy which has an impact on the carer or child/adult
- Any aspect of the assessment, reviews or care management

Each local authority has a designated complaints manager who receives all the complaints. They don't have to handle all stages of the complaint, but they are responsible for making sure complaints are dealt with swiftly and effectively.

For information on how to make a complaint, see the links to **Disability Rights UK** and **Contact** in the 'Making a complaint' section of our *Family Guide* resources page on our website: **www.dravet.org.uk/family-guide-resources**

You can also contact us directly for support and guidance at: **info@dravet.org.uk**

Transition to adulthood

When a young person with Dravet Syndrome reaches the age of 16, they have to transition to adult services. This involves significant changes in how care is organised and it can be an unsettling process for many families.

If your son/daughter is already an adult when they are diagnosed with Dravet Syndrome, you will have been dealing with adult services from the start. You may also be entitled to support via NHS Continuing Healthcare (see page 76).

If your child was diagnosed before the age of 16 and you already have a care plan in place, this will need to transition from child to adult services. Preparing for transition, in health, social care and education, should begin at the time of the 'Year 9 review', when a young person is 14. This might sound early, but it's important not to underestimate the time and effort involved.

"I started planning for our son's transition into adult services when he reached the age of 15. The best advice I can give is to invest plenty of time in your research. Talk to other parents and professionals, but don't rely on advice – find out for yourself and make your own plan. Make a list of what you need and cost everything out. You'll need to be prepared to have a lot of arguments on the way, but stick to your plan. Be prepared to be asked the same things time and time again. There's no getting around it. Again, doing your research helps. Read the pamphlets from adult services and quote these back at them, emphasising that all decisions need to be in the best interests of the young adult. If you know your stuff, you can get what you and your family needs."

Mum to a young adult with Dravet Syndrome

Legal deputyship – retaining legal responsibility for the care of your child when they turn 18

A young person with Dravet Syndrome legally transitions into adulthood at the age of 18. In England and Wales, to continue to be recognised as the primary decision-maker for their care, parents and guardians need to apply to the Court of Protection for a 'deputyship'. In Scotland, parents need to apply to the Office of the Public Guardian for a 'guardianship'. In Northern Ireland, applications should be made to the Office of Care and Protection.

You can apply to become a young person's 'deputy' or regional equivalent, if it can be shown that they lack capacity to make decisions about their lives. As a deputy, you can be legally authorised to make decisions on their behalf about their personal welfare, medical treatment, where they live, their financial affairs and other day-to-day matters.

If you don't have deputyship, legal responsibility for the young person with Dravet Syndrome won't automatically rest with you when they turn 18. The local authority will be entitled to take decisions which you may disagree with, and you will not necessarily have the ultimate say in decisions involving your child.

This doesn't mean that, as a parent/guardian, you will no longer be expected to care for your child or support them to make day-to-day decisions. But it does mean that you will no longer have sole responsibility for decisions regarding their personal welfare. Therefore, big decisions may not be left to parents or the young person to make by themselves.

There is more detailed information about managing the transition to adulthood in our *Transition Guide*. For a free copy, email: **info@dravet.org.uk**

NHS Continuing Healthcare for adults

NHS Continuing Healthcare (CHC) is a fully funded package of care available to adults in England who have particularly intense, complex or unpredictable care needs as a result of disability, accident or illness. It covers the full cost of the person's care in their own home, a care home or other residential settings.

If your child is aged 16 or older, you can ask for an assessment of eligibility for CHC funding at any time.

A young person who is already receiving Continuing Care for Children and Young People may be eligible for NHS Continuing Healthcare (CHC) when they reach the age of 18. It's important to note that the criteria for Continuing Healthcare are different to those for Continuing Care for Children and Young People. You can check if you're eligible for CHC when your child is 16 to 17. If they are, the transition to CHC should take place when they are 18.

CHC is not means-tested. To qualify, it must be proven that your adult has a 'primary health need'. This means that their care requirements are primarily for healthcare, rather than social or personal care needs. With Dravet Syndrome, this may include managing epilepsy, first aid for seizures, medication, mobility, feeding issues, managing challenging behaviour and many other potential health needs.

NHS CHC equivalents in the UK

In Wales, the CHC system operates in a very similar way to England. Scotland has a very different system, called Hospital Based Complex Clinical Care.

This system also funds personal care, which is a major difference to CHC in England and Wales.

At the time of writing, CHC services in Northern Ireland were limited.

Advice and information on NHS Continuing Healthcare

Navigating the Continuing Healthcare process can be complex and challenging – both for caregivers and professionals alike. **Beacon** is a not-for-profit social enterprise that specialises in helping people through the Continuing Healthcare funding process in England. You can contact their information and advice service for up to 90 minutes of free advice from their trained staff. They also have a free Navigational Toolkit written by expert caseworkers, which explains the system in detail, how to navigate each stage, and the pitfalls to look out for. Visit: **www.beaconchc.co.uk**

Citizens Advice and **Age UK** have information on Continuing Healthcare or equivalents in Wales, Northern Ireland or Scotland.

For links, see the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

You can also email us for support and guidance at **info@dravet.org.uk**

4. Financial support and your rights

As well as personal budgets and direct payments which are included as part of the social care plan (see page 73), there are a range of financial support packages available from the UK government to help families living with disabled children and adults. Families sometimes tell us they feel worried or embarrassed about applying for financial help. But please try not to. Caring for someone with Dravet Syndrome incurs extra costs; you and your family are entitled to receive as much support as possible.

Benefits, grants and other types of financial support change regularly, so we haven't included details of them all in this guide. Up-to-date information is available from:

- The **Contact** website, which provides comprehensive information about all forms of financial support available for families with disabled children.
- The **Turn2Us** website, a very useful resource, with all the tools you need to find out what kind of financial support your family is entitled to, whether government benefits or other types of grants, and how to go about applying for these.
- The **Cerebra** website, which provides free online guides for parents/carers on benefits and the grants system for disabled children, including how-to guides, myth busters and support with making complaints.
- The **Disability Grants** website, a comprehensive resource for identifying national and local grants to support the high cost of disability equipment, holidays, housing, days out and more.
- **Your local authority.** Did you know that many local authorities have welfare advisers who can help with claims for benefits? If you're already receiving social care via your local authority, try asking your social worker for the relevant person to contact.
- For one-to-one advice, you may also want to try the **Carers UK Helpline** or your local **Citizens Advice Bureau (CAB)**.
- The **UK government website** has up-to-date information about benefits and how to apply for them.

Dravet Syndrome UK offers a range of grants, assistance funds and awards. None of these are means-tested, but parents/carers do need to provide a letter confirming their child/adult has been diagnosed with Dravet Syndrome. The letter needs to be an official confirmation of diagnosis from the doctor or hospital.

At Dravet Syndrome UK, we're also here to provide practical help and advice. If you can't find what you're looking for, please email us at **info@dravet.org.uk** or call us on **01246 912 421**.

Follow these expert tips to avoid losing out on vital financial support:

- **Prepare early:** Don't wait for a crisis to happen before you apply.
- **Get expert advice before you submit any applications:** Families may find they are turned down for certain financial benefits because they haven't provided enough information in the right way. Always get someone who has relevant expertise to review your application for you. If you can't find anyone, email us at **info@dravet.org.uk** for advice.
- **Be honest, but don't downplay the impact of Dravet Syndrome:** The level of detail you provide in your applications needs to be based on worst case scenario.
- **Don't rule out non-means-tested grants:** Even if you don't qualify for means-tested support, there are many different types of grants available. These can still make a huge difference to your quality of life, so do consider these.

Wills and trusts

None of us like to think about what might happen when we die, but if you're a parent/carer of a child or adult with Dravet Syndrome, it's very important to plan for the future by writing a will. It's also a good idea to include a 'trust' in the will, as this gives you an opportunity to formally set out how your child/adult should be cared for when you die, as well as safeguarding their future finances.

There are several different options for creating a trust, such as a 'disabled person's trust' or a 'discretionary trust' managed by a group of beneficiaries. It's important to get expert advice on the best approach if you want to leave money or property to someone who can't manage their own finances, or who depends on benefits for a large part of their income.

- The **Mencap** website has a helpful Frequently Asked Questions section on wills and trusts.
- The 'Find an Adviser' tool on the **Turn2Us** website is a great source of information on creating wills and trusts, as well as many other legal issues. It has details of local, regional and national organisations in all areas of the UK.
- The **Contact** website also provides a helpful overview of wills and trusts, including useful links for more information.

Links to all these resources are available on the *Family Guide* resources page of our website:
www.dravet.org.uk/family-guide-resources

5. Education and your rights

All children and young people with Dravet Syndrome will need some additional support to help them learn and thrive. This could be for a variety of reasons. They may find it challenging to keep up with classes due to the intellectual disability associated with Dravet Syndrome. They may develop other conditions, such as autistic characteristics or attention deficit hyperactivity disorder (ADHD), which can affect their behaviour in social environments, such as school. (See 'Comorbidities' on page 29).

'Special Educational Needs' (SEN) is the term used in the UK to describe learning difficulties or disabilities that make it harder for children to learn, than most other children of the same age. SEN support helps with schooling, learning and development. There are usually two levels of support for children with SEN:

- **SEN support:** SEN support is available at all levels of education, from nursery to further education. This can be provided within mainstream schools or in specialist education settings. The support can take many forms. This could include:
  - A special learning programme for your child
  - Extra help from a teacher or a learning support assistant
  - Making or changing materials and equipment that can support your child's education
  - Working with your child in a small group
  - Observing your child in class or at break and keeping records of what they notice
  - Helping your child to take part in the class activities
  - Making sure that your child has understood things by encouraging them to ask questions and to try something they find difficult
  - Helping other children work with your child, or play with them at break time.
- **Education, Health and Care plans (known as an EHC plan or EHCP):** This is used when SEN support alone is not enough to meet a child's or young person's needs. An EHCP is invariably required to get a place in a specialist school. An EHCP applies in England. In Northern Ireland, the equivalent document is called a 'Statement of Special Educational Needs'. In Scotland, it's a 'Co-ordinated Support Plan' and in Wales it's an 'Individual Development Plan' (IDP).

If your child did not start school with an EHCP or equivalent, they will probably need to have SEN support for at least two terms before you can ask for an EHCP needs assessment. This is called a 'graduated approach'. Due to the intellectual disability and comorbidities associated with Dravet Syndrome, in almost all cases, every child with the condition will need a formal EHCP or equivalent in addition to any SEN plan developed with the school. For more on EHCPs and equivalents, see page 81.

SEN support in mainstream and specialist settings

Every child or young person with SEN has the right to support with accessing education, whether within mainstream settings or special needs schools. By law, every state school and nursery must provide SEN support. This includes academies and free schools but excludes private schools, as these are not obligated to provide SEN support.

It's never too early to get SEN support in place. Whenever your child starts a new school or nursery, or if they are already at school or nursery, ask for an appointment with the head teacher and special educational needs co-ordinator (SENCO) to explain your child's condition and their needs. All state schools have a SENCO. It is the SENCO's job to work with teachers, parents and health professionals to meet pupils' special educational needs and create a support plan with you, and if possible, your child.

Childcare and childminding services also need to be aware of any special needs requirements.

"Initially, I didn't want to send our son to special school. It's a hard thing to accept and can feel heart-breaking at the time. Especially if you're still coming to terms with the idea of learning disabilities, as we were. At the same time as feeling devastated, once he started the SEN school, it was also a huge relief. He was now in an environment that understands his behaviour and how to manage it. This took away some of the pressure and worry because it was just accepted. I thought: Okay, I can breathe now. I know he's looked after."

Mum to a teenager with Dravet Syndrome

There are no 'rules' as to whether your child with Dravet Syndrome should attend a mainstream school with SEN support or a specialist SEN school. Every individual and every family is different, so it's important to follow the path that's right for your child and your family's situation. This may be in a mainstream setting, at a specialist SEN setting, or a mixture of both. It's quite common for children with Dravet Syndrome to start out in mainstream settings and move onto specialist SEN schools as they get older.

There are upsides and downsides to both mainstream and SEN schools. It's important that whichever school you choose can meet all of your child's needs.

"My son attends a local special needs school and they have put measures in place to make sure he is safe. The difference in him since he started has been amazing. He now interacts with other children, plays with toys, and is learning to communicate. He is so happy when we arrive at school. He may not meet the milestones other children do, but he is one of the happiest children I know."

Mum to a six-year-old with Dravet Syndrome

"Through being at a mainstream school for a few years, our son has taught other children not to be scared of difference. Through meeting him, those children will carry that understanding and empathy that can only be a benefit to society."

Dad to a teenager with Dravet Syndrome

SEN support across the UK

The SEN system varies slightly across the UK. In addition, each local authority and state-funded school will have their own process and this can vary significantly between different areas of the UK:

- **England**: A child with SEN may go to a mainstream school, where there are pupils with and without SEN, or a special school, which only has pupils with SEN. There's more information on the UK government website in the 'schools and education' section.
- **Wales**: Visit the 'Help for families' section of the charity **SNAP Cymru's** website for more information about the special education system in Wales.
- **Scotland**: The system of support for children with additional support needs is called 'additional support for learning'. Visit the 'Advice for parents' section of the **Enquire** website to find out more.
- **Northern Ireland**: Visit the **Northern Ireland Education Authority** website or the charity **SENAC** for more information.

You can find links to all this information on the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

Education, Health and Care plans

An Education, Health and Care plan (known as an EHC plan or EHCP) brings your child's education, health and social care needs into a single, legal document. It's essential to ensuring your child has the right support in place to meet their needs. You always need an EHCP to secure a place in a SEN school, but an EHCP doesn't automatically mean that a child must go to a SEN school.

Putting an EHCP in place can feel daunting, and is easy to put off, especially in the early years when intellectual disability is not so apparent and managing seizures takes so much time and energy. Our advice is to apply as soon as you can. As with social care, the journey to getting a plan in place is not always easy. But having long-term support in place is well worth all the effort. Ultimately, it makes a really positive difference to quality of life for your child with Dravet Syndrome and all your family.

An EHCP applies in England. In Northern Ireland, the equivalent document is called a 'Statement of Special Educational Needs'. In Scotland, it's a 'Co-ordinated Support Plan' and in Wales it's an 'Individual Development Plan (IDP)'. The advice provided below relates specifically to EHCPs but also broadly applies to the process in Wales, Northern Ireland and Scotland.

How to apply for an EHCP or equivalent document

You need to start by asking your local authority for an 'education, care and health (EHC) needs assessment'. Anyone else who thinks an assessment may be necessary can request one – this includes doctors, health visitors, teachers, parents and family friends.

It's easier to get an EHC needs assessment if your school agrees. If the school doesn't agree, you can still ask your local authority for an assessment.

Based on your application, the local authority will decide whether or not to assess your child or issue a plan. The assessment will be based on conversations between the local authority and a number of people, including you and your child, their school or nursery, your doctor and an educational psychologist. Once the local authority has collected all the information it needs for the assessment, it will decide whether or not a plan is necessary. If they decide not to proceed with a plan, they must inform you within 16 weeks of the initial request.

Applying for an EHCP or equivalent can be daunting. The good news is you don't need to do it alone. There are expert organisations who can support you with an EHCP application, for example Independent Provider of Special Education Advice (IPSEA) and Special Educational Needs and Disability Information Advice and Support Services (SENDIASS). See 'Additional information and advice' on page 84.

Developing the EHCP or equivalent document

When drafting the plan/statement/assessment document, your local authority should work closely with you and your child to make sure the plan takes full account of your views, wishes and feelings. Once the plan has been written, a draft will be sent to you for reviewing.

Your local authority has to review your child's EHCP or equivalent document at least every 12 months. A meeting with you and your child must be part of this review so you can discuss your needs. This is an opportunity to update the plan to make sure it's still relevant and will help your child progress and develop. It's important that you provide an honest account of how you feel your child is progressing and raise any concerns you have. You can also suggest ways you feel this can be improved or any further support you think would benefit your child.

Tips to help you through your child's educational journey

- Keep track of your child's learning and progress. If possible, try to understand and follow their schoolwork and encourage them to continue learning at home.
- Arrange regular meetings to discuss your child's progress. Let the school know what's going on at home, and discuss areas you feel need developing. Don't be afraid to ask for additional support or make suggestions to improve your child's experience.
- Talk to your child about how they are enjoying school. Where possible, involve them in decisions about their education.
- Research SEN support services that are available in your area through your local authority. Discuss any concerns you have with a health professional. Talk to other parents who have children with intellectual disabilities.
- Ask the school to provide a home-school diary so that you and your child's teachers can share information each day.

If your child has an EHCP or equivalent you may be entitled to a personal budget, which allows you to have a say in how the money is spent to support your child.

You have the right to appeal if you disagree with your child's final EHCP or equivalent, or if you disagree with the local authority's decision not to provide one. There's information on how to appeal on the government website: **www.gov.uk/appeal-ehc-plan-decision**

Transition to adulthood and adult learning

Young people with Dravet Syndrome can continue in SEN schools until the ages of 16 to 19. Then, as with medical and social care, they will need to transition to adult services.

An important milestone for young people with Dravet Syndrome, as with all young adults, is the decision to attend school or college, or live away from home in a residential and/or supported living setting (see page 90).

A specialist further education college provides education for young people with SEN. Some have residential facilities and provide what is commonly called a 'waking day' or '24-hour' curriculum. Some specialist colleges help their students to attend courses in mainstream colleges.

Your local authority is responsible for funding specialist education for children and young people up to the age of 25. To go to a specialist college, a young person with Dravet Syndrome needs to have an EHCP or its equivalent in Wales, Scotland and Northern Ireland. These documents state whether a young person requires specialist provision beyond what a day school can provide.

You can ask the local authority to specify the name of a particular specialist college in their EHCP. They may refuse your request on the grounds of cost, and it may be necessary to show that there are no alternative cheaper education options available that are suitable to support the specific complex needs of your young person with Dravet Syndrome. Placements should be reviewed each year as part of the annual review of the EHCP or equivalent document.

"My daughter has just turned 17 and transitioned into a post-16 college. It's still part of the same school, but she's gone into the college section of it now. I wasn't sure it was going to work, with her being so sensory and not wanting to learn and things having to be on her terms, but they've adapted things to suit her. She has a full sensory timetable and she is out every day doing something in the community, which is fabulous and really works for her."

Mum to a teenager with Dravet Syndrome

Additional information and advice

You can find more information and advice on schooling and education for children and young people with complex needs through the following organisations:

- **Independent Provider of Special Education Advice (IPSEA)** offers free, expert advice to families, including a one-to-one advice line and template letters.
- **The Special Educational Needs and Disabilities Information Advice and Support Services (SENDIASS)** provides free and impartial advice and support for parents/carers. Every county in England has a SENDIASS.
- **Special Educational Needs Advice Centre (SENAC)** provides information, advocacy and advice in relation to SEN law in Northern Ireland.
- In Scotland, parents/carers can contact **Enquire**.
- In Wales, parents/carers can contact **SNAP Cymru**.
- **The Council for Disabled Children** website includes helpful examples of good practice.

Other useful organisations to contact include:

- **National Association of Family Information Services**
- **Contact**, the charity has a useful education and learning section on their website
- **Cerebra**, the charity has a comprehensive guide to education
- **Your local authority**
- **Department for Education**

You can find website addresses for these organisations, as well as other useful links, on the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

6. Respite care or short breaks

Caring for a loved one with Dravet Syndrome is a full-time job. It demands a lot of energy, so it's vital you take care of your own health and wellbeing. An important part of this is making sure you take some time off from your caring responsibilities. You need regular breaks to stop you getting exhausted or run down and also to give you and your family the opportunity to do things other people take for granted. This includes spending time with other children and family members, catching up on sleep, or even just having time to stop and think. Having time apart can also improve your relationship with the person you care for.

'Respite care', also called 'short breaks', is a term used to describe a time when your child/adult is looked after by someone else, often a professional carer. This could be for a couple of hours, overnight, a weekend or longer. During that time, you have a much-needed break from caring responsibilities. There are lots of respite care options, including: home care, day care centres, hospices or residential care homes. You'll find more details on each of these on pages 85 to 87.

We understand it can be difficult to trust other people to care for your loved one. Some people can feel guilty about taking breaks. But respite care is now well recognised to be a vital service which helps families to lead 'ordinary lives'. It's important to remember that using respite care to help you recharge not only benefits you and your family but also your child/adult with Dravet Syndrome. It offers them a change of scenery, different experiences and the opportunity to have fun and make friends.

Start to think about respite care as soon as possible in your caring journey. It might take a while to arrange it, so don't wait until you feel you need it.

Ask your local authority for their 'short breaks statement'

Local authorities usually have a legal duty to provide short breaks for carers and disabled children or adults. They must make it clear how families can access these by providing a 'short breaks statement'.

A short breaks statement should set out:

- The range of services available
- Eligibility criteria for using the services
- How these services are designed to meet the needs of families with disabled children in their area

A short breaks statement must be available on request – most local authorities publish it on their website as part of their 'local offer'. (A local authority's 'local offer' gives children and young people with special educational needs or disabilities and their families information about what support services will be available in their local area). The statement is meant to be reviewed at least once every 12 months.

For more information, visit your local authority's website and search for 'local offer' or 'short breaks'.

What can you do if your local authority says no to short breaks?

We wish we could say that access to respite care will be straightforward following an assessment. Unfortunately, you may not be offered it without repeatedly asking. It's quite common to hear statements like, "Our local authority no longer provides respite/short breaks" or, "We don't do carer's assessments in this local authority". However, these statements are unlawful. In fact, the local authority should not put a blanket ban on any service and should always consider the needs of the individual child and family.

Sometimes parents/carers are put off applying for short breaks because they feel that their need is not as great as it is for others. But there is no reason to think that you're taking a place from someone else. Try to focus on your family and getting the best you can for them.

Be prepared to fight for what you're entitled to. No one likes to be the 'difficult' parent/carer. But sometimes you will have to challenge what you're told and keep pushing to get the resources your family needs and has every right to have. If you're successful, social services will provide respite care directly, or you may be offered 'direct payments' (see page 73), which you can use to organise and pay for it yourself.

Different types of short breaks

In the home

Sometimes called 'homecare', this is where you arrange for a paid carer to help you at home. It might be regular, for example, one day a week so you can work, study or have a day off. Or, for a short period, like a week or fortnight, so you can take a holiday.

Some charities and carers' organisations offer 'sitting services', where a trained volunteer keeps a child or adult company for a while, usually a few hours at a time. This type of service is often free, or there may be a small charge.

If you need it, you can arrange live-in care or an overnight sitting or nursing service.

Where to find out more
Your local council may have a directory of homecare agencies in your area on their website, or you can ask their social care department for information. The **Homecare Association** has a list of approved homecare agencies in different areas, and **Carers Trust** also provides information on homecare services.

For details of these organisations, visit the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

In another family's home

'Family Link' is an overnight short break service where a child with disabilities stays with another family in their home on a regular basis or occasionally. Children will be carefully matched with approved carers.

Where to find out more
You can ask the social care department of your local authority if they have a Family Link service.

Day care centres

Children and young people can be cared for at a range of day centres. This includes nurseries; playgroups; out of school, weekend and holiday clubs; and play and activity schemes. There are also some day care services for disabled adults.

Where to find out more
Search on your local authority's website for day care centres in your area. Also have a look at charity websites such as **Scope** and **Mencap**.

"Our daughter now attends Fairplay which is a brilliant centre for young adults aged 16 to 25. She loves it there. She attends four days a week and she also goes to Fairplay for 'sleepovers'. This provides respite for her and is an opportunity to get away for a while and spend time with her friends. And, of course, it gives us a chance to have a much-needed break. She takes part in lots of clubs and activities at Fairplay, including the Big Dance Project, The Signing Choir, as well as learning other new skills. Some days she may go for a pub lunch or to the cinema. She has even been on a Christmas shopping trip to Bruges! Our daughter's life is quite fulfilled now which is what we really wanted for her."

Mum to a young adult with Dravet Syndrome

Breaks at hospices or residential homes

It can be difficult for families to think of hospices as a place for caring breaks, as they are most often associated with end-of-life care. However, many hospices also provide regular short breaks and can help with homecare. Although hospice placements can be hard to find, people with Dravet Syndrome are definitely eligible for them. This is because Dravet Syndrome is a 'life-limiting' condition (a term used by the NHS to identify children and adults who are entitled to support from hospice care services).

Where to find out more
Search online to see if there's a hospice or residential home near you that offers short breaks. If so, arrange to go along for a visit.

"We get 18 nights a year when our daughter spends the night at the hospice. We sometimes use that time to get some quality time just with her sister, and sometimes she goes for a sleepover too, so we get some time together as a couple."

Mum to a 15-year-old with Dravet Syndrome

"We have been very lucky to have access to our local children's hospice and they have been amazing. Our son can stay overnight. This gives us time to recharge and spend some time with his brother, doing the things he enjoys that may not be suitable for our son with Dravet Syndrome. I was unable to return to my full-time job after maternity leave, and once he was over 18 months, I could not find a nursery that met his needs. So, he went to Day Support at the hospice every Monday. They helped him develop a number of skills and take part in organised activities. He played in the sensory room and everything was suitable for him. He had so much fun with the staff and volunteers. They also have a hydrotherapy pool which he loves and is great for his muscle tone. They don't just support and care for him but for the whole family too. I have also made friends with other mums and we support each other."

Mum to a six-year-old with Dravet Syndrome

Respite holidays

Respite holidays allow parents/carers and children/adults with Dravet Syndrome to take a longer break from everyday life.

Where to find out more
The **Family Holiday Charity** has breaks at holiday sites, or grants to help with the cost of a holiday, for families on low incomes. You need to be referred by your social worker, GP or health visitor, or by a charity.

Search online for other organisations offering these services, such as **Revitalise**, which has purpose-built holiday centres.

For links to respite care information, visit the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

Care from family and friends

Trusting a family member or friend to look after your child/adult with Dravet Syndrome can be a big step, no matter how close your relationship. It's particularly hard when children are younger and experiencing a high number of seizures. We understand that not everyone has family and friends in a position to help. But if there is someone you trust who offers support, take time to consider it, and think about what you would need to do to make it work. While friends and family might not be professional carers, in many cases, they will be an expert in understanding your family's needs.

Spend time together first to make sure they are comfortable and confident about looking after your child/adult with Dravet Syndrome, and that they know exactly what to do in an emergency.

Practical things you can do to help both you and the person providing caring support to feel confident include:

- Ask your epilepsy nurse to help organise a training session.
- Build up the time and distance slowly – start with short breaks while you stay in the house or nearby (you could go for a bath or a walk).
- Make sure your emergency protocols and key contact numbers are up to date and that you've shared these with your friend of family member. (See page 49 for more information on emergency protocols).

Emergency respite care

While most respite care is planned ahead of time, emergency respite care is arranged at short notice, as and when it's needed. You might arrange it if, for example, you feel as though you urgently need a break, you fall ill or have an accident, or you need to go and take care of someone else in the family.

Think about who you could contact in an emergency if you couldn't be with your child/adult. This might be another relative, friend or neighbour who could step in for a few hours while proper arrangements are made. You could also check with your local authority if they offer emergency respite care.

Make sure an emergency carer:

- Has door keys or knows the code to a key safe.
- Knows the type of care the person you look after will need – this may be simply sitting and chatting with them, making a meal, or helping them take their medicines.
- Has some notes about what kind of care the person you look after needs, including essential information on medicines, and any dos and don'ts. Leave these notes in a prominent place for your emergency carer to find.

Paying for respite care or short breaks

How you pay for respite care depends on the type of break you need and your personal circumstances. It might include funding from the local authority or a grant from a charity.

Funding from the local authority

Local authorities will only pay for respite care for people who they've assessed as needing it following a needs assessment (page 69) and carer's assessment (page 72). If you haven't had these assessments already, or it's been some time since your last one, we very much encourage asking for them. If you or your child/adult with Dravet Syndrome qualifies for respite care, the local authority will do a financial assessment to work out if it will pay towards it. If you qualify for local authority-funded respite care, you can ask them to arrange it for you, or you can do it yourself through a personal budget or direct payment. For more on personal budgets and direct payments, see page 73.

Grants from charities

The charity **Carers Trust** offers grants for respite care. You will need to apply through your local Carers Trust service. They can explain everything you need to know about who qualifies and help you apply. They may also be able to let you know about other ways to pay for respite care.

The charity **Turn2us** can help you find grants for respite care. There's more information about paying for respite care on the NHS website.

'**Benevolent funds**' can sometimes offer grants for respite care. Benevolent funds are a type of charity, usually linked to trades, professions, unions, geographical areas or the armed forces, that can help people during bad times, for example illness, unemployment or other difficult circumstances.

For links to information about paying for respite care, visit the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

7. Living options for young people and adults with Dravet Syndrome

When you have a loved one with Dravet Syndrome, there are four main options for where they live:

- The family home
- Supported living
- Residential care
- Their own home with carer support

We've included more details on each of these on pages 91 to 94. Which you choose will depend on the individual needs of your young person/adult with Dravet Syndrome and your personal circumstances. This can include your home, work and financial situation, as well as the support available from your local authority and other support networks.

Finding the most suitable living situation that provides the best quality of life for your young person/adult is an incredibly important decision. Understanding the different options is the first step. Try to take your time to weigh up the positives and negatives of each option. And if your young person/adult has the capacity to do so, involve them as much as possible in the decision.

If you have other children, talk to them too. Where your young person/adult with Dravet Syndrome lives affects all the family. The decision you make needs to be right for everyone.

We understand it can be difficult for any parent/carer to adjust as their child becomes an adult, particularly when they need a lot of support. There can be feelings of guilt or failure. But try to focus on the positive aspects

of independent living for your young person/adult and the new experiences it will bring.

Discuss the situation with other parents/carers. The Dravet Syndrome UK private online forum is a good place to find people who have had to make similar choices.

For more information on the forum and other support available, visit the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

Whichever living option you decide on, it can be a stressful – and lengthy – process. Suitable residential properties and places are few and far between. Depending on where you live, your local authority may have preferences based on availability and cost. For example, it's cheaper for a local authority to fund someone in a supported living housing than in residential care. You may need to fight to get the accommodation that you've decided is right for your young person/adult.

We're here to offer guidance and support. Email us at **info@dravet.org.uk**

Securing the funding you need

How much choice and control families have over where their young person/adult with Dravet Syndrome lives will depend on funding and availability. It's essential to get the right funding in place as soon as possible. It's likely to come from a combination of social services and NHS Continuing Healthcare (see page 76), which is a package of care available to adults with complex care needs and covers the full cost of the person's care in their own home, a care home or other residential settings.

Your first step to securing funding is contacting your social worker. (If you don't have one, you will need to arrange a 'needs assessment' – see page 69).

For advice on NHS Continuing Healthcare and more on how to get the funding you're entitled to, visit: **www.beaconchc.co.uk**. Beacon is a not-for-profit social enterprise that specialises in helping people through the Continuing Healthcare funding process in England.

Citizens Advice and **Age UK** have information on Continuing Healthcare or equivalents in Wales, Northern Ireland or Scotland.

For direct links, see the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

You can also email us for support and guidance at: **info@dravet.org.uk**

In the family home

Having considered the alternatives, you may decide that the best living option for your young person/adult with Dravet Syndrome is to stay with you in the family home.

When your child becomes an adult, your local authority should review the package of care you receive and assess you as a carer of an adult.

There is more detailed information about managing the transition to adulthood in our *Transition Guide*. For a free copy, email **info@dravet.org.uk**

You may need to make additional adaptions to your home as your child becomes an adult, such as building a wet room if you don't already have one. The NHS information on 'Home adaptions' is a good starting point.

For links to this information, visit the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

Planning ahead

If you decide your young person/adult with Dravet Syndrome is going to continue living at home, you'll need to plan for when you get older and being a carer becomes more difficult. So, you may find it's helpful to research residential and supported living options anyway, even if you don't decide to access them right now.

Supported living

Supported living, or supported housing, refers to when people live away from their parents in their own home, or share a home with other people with a similar health problem or disability. In supported living situations, people usually have some form of care, for example help with shopping, cooking, washing and other everyday tasks.

People usually have their own bedroom and communal spaces. Types of supported living accommodation can vary considerably and it's a case of finding one with the right level of support for your young person/adult.

One of the positives of supported living is that residents and their parents/carers can have some say over the way things are run and the care provided. Buildings and services can be designed to meet individual needs.

Supported living services are provided by local councils or charities, or they may be run by commercial companies. Funding includes government benefits, such as housing benefits, local authority funding and personal budgets.

Local authorities will often have some preferred providers of supported living services, but individuals can also contact providers directly to see whether they can help.

A note on terminology

Supported living that includes on-site staff, meals or personal care is sometimes called 'extra supported living' or 'extra care housing'. This is often talked about alongside 'sheltered housing' which can make people assume it's just for older people. But it's also for young people/adults with additional needs and disabilities who need 24-hour support. Different local authorities use different terminology, so it can be confusing. Don't hesitate to ask people to clarify what services they are offering.

The NHS has a list of housing options in their social care and support guide.

You'll find a direct link on the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

"Our son is now living in his own home, with 24/7 supported living care, funded by Continuing Healthcare. We've developed his care package ourselves and we directly employ the carers. Most days we visit his house to ensure everything is running smoothly. Most of the time, he lives a supported independent life. People are told: 'These are your options – supported living, residential care or muddle through at home with a limited amount of support'. It doesn't have to be like that.

You decide what you think is best for them. You have to fight for it, but we always had a long-term goal for our son, that when we retired, we would pull back. We want other parents to know that you don't have to accept residential care if that's not what you want. We've now set our son up for the rest of his life and for when we aren't here anymore. His sister is part of the team and is his deputy, so we know he will be okay in future. He is our whole lives."

Mum to a young adult with Dravet Syndrome

Residential care

Residential care homes provide 24-hour care onsite. They vary in size and can house between four and eight people, sometimes more. The number of staff varies depending on the needs of the residents. Your local authority's adult social care department can tell you what residential homes are in your area. Places tend to be extremely limited.

Benefits of residential care homes include having other people around to socialise with and organised activities, either in the home or during planned trips.

When considering a residential home, you'll need to think about whether it meets your young person's/adult's needs. Your young person/adult would need to have a needs assessment (see page 69) first. If you fit the criteria, the local authority normally funds the residential home place.

Regulating residential care homes

Residential settings which care primarily for people over 18 (or children for more than 295 days per year) are regulated by:

- The Care Quality Commission in England
- The Social Services Inspectorate in Wales
- The Care Inspectorate in Scotland
- The Regulation and Quality Improvement Agency in Northern Ireland

You can find website addresses for these organisations on the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

Things to consider when choosing accommodation for your young person/adult with Dravet Syndrome

- Take time to make sure the residential care home or supported living service fully understands your child's needs. Ask if they have any experience of Dravet Syndrome or similar conditions.
- Check the staff to resident ratio is high enough for your young person's/adult's needs.
- Find out everything you can about the care home or house and make sure it has everything your young person/adult will need before you agree to move in. For example, does it have accessible wet rooms? A secure garden? It can be difficult to change accommodation once you've moved in.
- Ask to see the service provider's safeguarding policy. You'll need to feel confident that the accommodation is safe and your young person/adult is being looked after. Also ask what the process is if you do have an issue or complaint.
- Ask about social activities available in the home or nearby. Does the home have a timetable of activities or organise any trips? You'll want to make sure your young person/adult has things to do and can live life to the full.
- Local authorities will have preferred suppliers. But don't feel you have to go along with what the local authority tells you. You can contact service providers and arrange to visit the homes yourself.

Home ownership

There are several options for people with Dravet Syndrome to buy their own property. For example, by entering into a shared ownership agreement, where the person owns a percentage of the property and the rest is owned by a housing association. This might be funded by investment from the family, or a help to buy scheme. There are also options to buy a home together with a number of other people.

If you're considering a mortgage and your young person/adult is entitled to certain benefits, such as Disability Living Allowance or Personal Independence Payments, they may be able to claim an additional benefit called Support for Mortgage Interest (SMI).

Mencap's housing advice and support covers all the living options mentioned in this section and more. You'll find a direct link on the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

For direct links to all the online resources mentioned in this guide, please visit the *Family Guide* resources page of our website: **www.dravet.org.uk/family-guide-resources**

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Dravet Syndrome UK
PO Box 756
Chesterfield
S43 9EB

Tel: 01246 912 421
Email: info@dravet.org.uk

@DravetSyndromeUK
@DravetUK
Dravet Syndrome UK

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