DRAVET
Syndrome UK

The transition from child to adult services

A guide about moving into adulthood for parents and carers of young people with Dravet Syndrome

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About Dravet Syndrome UK

Dravet Syndrome UK was set up 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 16+ Assistance Grant for young people and adults. We bring families together, whether online through our community forum or at 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 the condition. 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.

Get in touch

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**

About this guide

Welcome to Dravet Syndrome UK's guide to the transition from child to adult services. Here we bring together facts, expert guidance and practical tips to support you through this key milestone in the life of a young person living with Dravet Syndrome.

1 The first part of this guide covers the key areas affected by transition: legal rights, healthcare services, access to social care and education, learning and living options, and financial support.

2 The second part discusses the impact that becoming an adult can have on life inside and outside the family home.

Don't be scared, be prepared

Becoming an adult is a big change for any child. As a parent/carer to someone living with Dravet Syndrome, the transition to adulthood can feel very daunting. There's a lot of information out there and you may hear some negative stories. The reality is that there are ups and downs involved in the transition process. With this guide, we're here to hold your hand throughout the journey and to help you through those ups and downs.

We'll empower you with knowledge and advice to help you plan for your child's future in a positive and managed way. You'll know your rights and understand the options ahead. And if you can't find the exact information you're looking for, you should find links to other organisations and services with the specialist knowledge to support your needs.

If there's one piece of overarching advice in this guide, it is 'don't be scared, be prepared.' Start planning early, do your research and ask for help if you need it.

If you are reading this guide as the parent/carer of a teenager, you will have lived with Dravet Syndrome long enough to know that one of the few predictable things about the condition is its unpredictability. No matter how diligently you plan, unexpected issues and challenges will come up.

That's why we advise planning for transition early, when your young person living with Dravet Syndrome reaches the age of 13.

Being prepared also means being ready to take control at certain points in your transition journey. You may need to push for the information and support you need to help create a future that's right for your young person.

You're not in this alone. Turning to others with relevant expertise or experience is part of preparing for transition, so don't be afraid to ask for support and advice if you need it. The good news is that there is plenty of support out there.

On the DSUK Facebook Forum, you'll find there's hundreds of families who have already been through transition. Our Family Support team is also a source of expertise and guidance. As with all our resources, this Guide is informed by the real-life experiences of families living with Dravet Syndrome and guided by the expertise of medical professionals.

The journey ahead

Everyone's transition journey is different. It will partly depend on individual circumstances and where you live. Given the complexity and variation in transition services across the UK, we can't promise you will find all the answers you need in this Guide.

What you will discover is plenty of helpful information and advice, giving you the knowledge and confidence needed to navigate the journey ahead and create a happy and fulfilled life for your young person living with Dravet Syndrome.

Galia Wilson, Chair of Trustees at Dravet Syndrome UK

Note: The information in this guide was compiled by Dravet Syndrome UK. All information was correct at time of publication in February 2025.

PART 1 Planning for the move from child to adult services

Understanding the legal impact of someone with Dravet Syndrome becoming an adult

The legal age of becoming an adult is 18 across England, Northern Ireland and Wales, and it's 16 in Scotland. Once someone reaches the legal age of adulthood, legal responsibility for their care will no longer automatically rest with you as their parent or carer – even when they have a condition like Dravet Syndrome.

Due to the intellectual disability associated with Dravet Syndrome, most young people living with the condition will either lack mental capacity or have partial capacity. In these cases, there are several options that you can choose from as a parent or carer that allow you to make decisions about their health and welfare as an adult.

It's important to consider these to make sure you still have a say, legally, in your young person's care. It can be difficult to think about, but it's a good idea to plan ahead and consider what should happen in the longer term, when you may not be able to do so much or are not around.

Use this section of the guide as a starting point for your own research. We'd encourage you to speak to other people who've been through the transition from child to adult services and discuss it with your family and those who support you.

There's no right or wrong answer. The decision needs to be the right one for your young person, you and your family.

Once someone reaches the legal age of adulthood, legal responsibility for their care will no longer automatically rest with you as their parent or carer – even when they have a condition like Dravet Syndrome.

What is mental capacity?

Mental capacity is about your young person's ability to make a particular decision at the time it needs to be made. It means they can:

- **Understand information**
- **Remember information**
- **Explain their decisions**
- **Understand the consequences**

In **England** and **Wales**, the **Mental Capacity Act 2005** is an important law. It applies to people aged 16 and over who can't make decisions for themselves and provides the legal framework for acting and making decisions on their behalf as a carer or parent.

Making decisions in someone's 'best interests'

The Mental Capacity Act states that if someone lacks capacity to make decisions, the person most directly involved in their care, like a parent or carer, can do so and it must be in the person's '**best interests**'. This means that decisions made, or actions taken on behalf of someone who doesn't have mental capacity, must take various factors into account. Factors include their wishes and feelings.

There are standard steps to follow when deciding someone's best interests. These are set out in Section 2 of the Mental Capacity Act Code of Practice.

For complex decisions, like whether someone should have a serious operation or where they live, a doctor or another healthcare professional can assess your young person's mental capacity through a **mental capacity assessment**. This will involve them asking questions to see if the young person can make decisions.

Anyone who works with or cares for a young person who lacks capacity must follow what the act says when they make decisions about their life.

Find out more about how mental capacity is assessed here: **www.mind.org.uk/information-support/legal-rights/mental-capacity-act-2005/capacity/#HowIsMyMentalCapacityAssessed**

It's a good idea to become familiar with the Mental Capacity Act 2005. You can download an easy to read guide to the act here: **assets.publishing.service.gov.uk/media/62321dcae90e070ed943236f/MCA-easy-read-summary-booklet.pdf**

In **Scotland**, the relevant law that assesses mental capacity is the **Adults with Incapacity (Scotland) Act 2000**: **www.gov.scot/publications/adults-with-incapacity-act-principles**

In **Northern Ireland**, it's the **Mental Capacity Act (Northern Ireland) 2016**: **www.health-ni.gov.uk/mca**

You can set up a lasting power of attorney (LPA)

An LPA is a legal document that allows you (the attorney) to make decisions on your young person's (the donor's) behalf when they don't have capacity to make decisions for themselves. If your young person with Dravet Syndrome has the capacity to choose someone they trust to make decisions about their life, you could become their attorney. This applies if you live in England or Wales.

There are two types of LPA:

1. Property and financial affairs LPA. This allows you to manage your young person's financial affairs.
2. Health and welfare LPA. This gives you the right to make decisions about treatments, including life-sustaining ones. A health and welfare LPA gives you the power to consent to or refuse treatment.

How do you apply for an LPA?

An application for an LPA must be made by the young person themselves, but they can be supported to do so. They must be over 18 and have the mental capacity to make the application. That means they must understand the information and decisions they are making.

Is there a cost?

Yes, but these can be waived if your young person is receiving benefits or reduced by 50% if they have an income below £12,000 a year. At the time of writing (2024), the cost for each LPA is £82. So, that's £164 If you want to apply to both property and financial affairs, and health and welfare LPAs.

Where do I find out more?

In **England** and **Wales**, find out more about LPAs here: **www.togetherforshortlives.org.uk/get-support/supporting-you/family-resources/lasting-powers-of-attorney-and-deputyship**

In Scotland: **www.mygov.scot/power-of-attorney**

In Northern Ireland: **www.nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney**

You can apply for 'deputyship', 'guardianship' or to become a 'controller'

If your young person does not have capacity to choose an LPA, you can apply to the courts to become their legal 'deputy'. This will allow you to make certain decisions on their behalf. There are two types of deputyships:

1. Personal welfare, where you can make decisions about their medical treatment and care.
2. Property and financial affairs, where you can make decisions about their finances, where they live and other day-to-day matters.

For deputyship to happen, it has to be shown that your young person lacks capacity to make decisions about their life. A doctor or other healthcare professional can assess mental capacity.

Once a deputyship order is issued, it allows you, as a deputy, to act in the best interests for your young person. However, there are limitations. For example, the deputy cannot demand treatment that a medical team does not believe is in the person's best interests.

If your young person already has an LPA, they don't usually need a deputy.

Is there a cost?

Yes. There's an application cost of £408 per deputyship at the time of writing (2024). There's also an annual supervision fee which varies according to the type of deputyship.

But, these costs can be reduced depending on your financial circumstances and how much money you or the person you're applying to be deputy for has.

If you're applying for a property and financial affairs deputyship, your young person's finances will be assessed. If you're applying for a personal welfare deputyship, your finances will be assessed.

Where do I find out more?

You don't have to get legal advice to become a deputy, but it may help if your family or financial situation is complex.

In **England** and **Wales**, the Office of the Public Guardian (OPG) provides advice on becoming a deputy. Contact them on **0300 456 0300** or **customerservices@publicguardian.gov.uk**

In **Scotland**, contact the OPG on **01324 678 300** or **OPG@scotcourts.gov.uk**

In **Northern Ireland**, contact the Office of Care and Protection on **0300 200 7812** or **OCP@courtsni.gov.uk**

How do I apply?

In **England** and **Wales**, to obtain deputyship, parents and carers apply to the **Court of Protection**, a court that deals with decision-making for adults who may lack capacity to make specific decisions for themselves. You can apply to be a personal welfare deputy or a property and financial affairs deputy here: **www.gov.uk/become-deputy**

In **Scotland**, you need to apply to the **Office of the Public Guardian** for a 'guardianship': **www.publicguardian-scotland.gov.uk/guardianship-orders**

In **Northern Ireland**, applications to become a 'controller' are made to the **Office of Care and Protection**: **www.justice-ni.gov.uk/articles/how-apply-become-controller**

Applications usually take between four and six months, but they can take longer, so make sure you start this process well before your young person turns 18.

You can become an 'appointee'

If the young person with Dravet Syndrome lacks mental capacity, as their parent or carer you can apply to the Department for Work and Pensions (DWP) to become an appointee to manage their benefits. The benefits are then paid to you.

You don't need to do this if you already have the right to manage your young person's benefits. If you have been appointed as the young person's deputy, for example.

Being an appointee just gives you the legal responsibility for their benefits, not a say in other aspects of their life or care.

You apply to become an appointee by calling the DWP's helpline for a particular benefit: **www.gov.uk/become-appointee-for-someone-claiming-benefits**

You can choose not to apply for any of the options we've mentioned and rely on 'best interests'

'Best interests' means that decisions made, or actions taken on behalf of someone who doesn't have mental capacity, must take various factors into account. Factors include their wishes and feelings.

If you rely on best interests, as many parents and carers do, a lot will depend on the situation you're in and the team of health and social care professionals you're working with. The 'decision-maker' will normally be the carer responsible for the day-to-day care of your young person. It could also be a professional such as a doctor, nurse or social worker when decisions about treatment, care arrangements or accommodation need to be made.

More information on financial decision-making

Download this UK government toolkit for parents about making financial decisions for young people who don't have capacity to make their own decisions: **www.gov.uk/government/publications/making-finance-decisions-for-young-people-parent-and-carer-toolkit/making-financial-decisions-for-young-people-who-lack-capacity-a-toolkit-for-parents-and-carers**

Visit the Dosh website. This is an organisation that supports people with learning disabilities to manage their money: **www.dosh.org**

Moving from child to adult healthcare services

In the UK, children's and adult's healthcare services tend to be quite separate from each other and structured in different ways. Your medical team may be comprised of healthcare professionals with different roles, job titles and responsibilities to those that you're used to seeing in child (also called 'paediatric') services. This means that adult services can look and feel different to child services.

In the following section, we share some guidance, tips and tools to help you prepare for the medical and healthcare related aspects of transitioning from child to adult services.

Who is responsible for the transition to adult healthcare services for young people with Dravet Syndrome?

In **England**, your local Integrated Care Board (ICB) is responsible for making sure the transition from child to adult services is put in place.

In **Wales**, the responsibility for the transition to adult healthcare services lies with Local Health Boards or NHS Trusts. In **Scotland**, it's regional Health Boards and in **Northern Ireland**, it's the Health and Social Care Board.

> “Transition was a very scary and stressful time. We had absolutely no idea that it was going to be so difficult to access what our daughter needed to move into adult services. This guide should enable others to be forewarned and forearmed.”

Dad to a teenager with Dravet Syndrome

National guidelines for transition in epilepsy services

There is no specific blueprint for transitioning the care of a young person living with Dravet Syndrome (or other epilepsies) into adult services. However, there are standards of care and guidelines for transition which all local authorities and regional areas of the NHS need to follow.

These include:

- National Institute for Health and Care Excellence (NICE) guidelines in England and Wales
- Scottish Intercollegiate Guidelines Network (SIGN) guidelines in Scotland
- *National bundle of care for children and young people with epilepsy* standards of care from NHS England

See the box to the right for useful links to these guidelines.

Some areas of the UK will have more developed transition services than others. So it's important to be aware of the key points from these guidelines, including:

- **All children and young people with epilepsy should have a designated 'named worker'.** They are responsible for initiating and planning for the move from child to adult services. This named worker will most likely be a social worker but could be a nurse, youth worker or another health, social care or education practitioner, allied health professional, key worker or GP. The named worker should help coordinate transition across different services. In this section, we focus on healthcare. See page 18 for more information about moving from social care and other support services.
- **To support them with processing the move from child to adult services, all children and young people with epilepsy should have access to an epilepsy specialist nurse.** Or they should have access to a community paediatric nurse if they have conditions that are managed under the community paediatric team.
- **Transition planning should begin early** (in year 9, around 13 years old) for young people who have complex or additional health and social care needs. For example, young people whose seizures are not yet controlled or those with learning disabilities.
- **Any support and resources for the transition to adult services should take into account any co-occurring conditions** (commonly described as 'comorbidities') and the complexity of epilepsy.
- During the transition period, **paediatric and adult multidisciplinary teams should jointly review your young person's diagnosis and management plan.** Services should involve the young person and their family or carers when planning and making decisions about their care.

Useful links

- NHS England: *National bundle of care for children and young people with epilepsy*: **www.england.nhs.uk/long-read/national-bundle-of-care-for-children-and-young-people-with-epilepsy**
- *Epilepsies in children, young people and adults*: NICE guideline [NG217] 27 April 2022. Section 11: Service provision and transition: 11.1 Epilepsy specialist nurses; 11.2 Transition from children's to adults' epilepsy services: **www.nice.org.uk/guidance/ng217**
- SIGN evidence-based clinical guidelines: *Epilepsy*: **www.sign.ac.uk/media/1968/sign-epilepsy-parent-carer-pat-booklet-2022.pdf**

How your medical team might change in adult services

The make-up of your new medical team will depend partly on where you live and the needs of your young person. Dravet Syndrome is a spectrum condition so individual needs can vary significantly in terms of seizures, intellectual disability and other co-occurring conditions.

Here's a brief (but not exhaustive) guide to the key changes you might expect:

- **Adult neurologist.** Your young person should be referred to an adult neurologist at a 'tertiary centre'. A tertiary centre is an NHS hospital or clinic that provides healthcare from specialists with specific expertise in a given field.

  Generally, there are fewer adult neurologists with expertise in Dravet Syndrome compared to paediatric neurologists. Adult neurologists tend to have a bigger caseload and cover a wider range of neurological issues, including looking after older people with conditions such as Parkinson's disease or dementia.

- **Epilepsy nurse specialist.** NICE guidelines say that transition should include access to an epilepsy nurse specialist who can provide information, education and support, and facilitate access to other community and multi-agency services. In some cases, this may be an adult learning disability nurse, rather than an epilepsy specialist.

- **Local/community adult neurologist and/or GP.** It's helpful to have a local point of contact who can prescribe medications and deal with general health-related enquiries. For this reason, it's worth getting to know your GP as you head towards transition, even if they have not had much contact with your young person up to this point.

  If your young person is on their GP's learning disability register, they will get an annual health check when they turn 14. These checks are a chance to ask questions and talk about what they need.

  When they reach the legal age of adulthood, you will need to apply for what's called 'proxy access' from the GP to be able to continue to act on their behalf. This includes ordering repeat prescriptions, booking appointments and accessing test results.

> “I have proxy access for my daughter at her GP. It allows me to have her profile on my NHS app, order repeat prescriptions and speak to surgery staff on her behalf. It's especially important once your loved one hits 18 years old. It's easy to set up. Just speak to your GP and bring in ID for you both.”
>
> Mum to a young person living with Dravet Syndrome

- **Adult learning disability clinician.** As part of planning for transition and depending on their individual needs, your young person may be referred to a learning disability clinician. For example, they may be referred if their seizures are relatively well managed. This may also include access to **occupational therapists** and other multidisciplinary specialists.

- **Mental health services.** If they use child and adolescent mental health services, your young person might still stay with the services until they are 25. This is if they start a treatment that isn't expected to be long term, before they turn 18.

- **Admission to hospital.** If your young person is admitted to hospital, and they are over 16, they are likely to stay on an adult ward. They probably won't be known to adult services yet. The adult ward may include much older people with lots of different medical needs. This can be uncomfortable, both for your young person and you. Be aware that visitors can't usually be on an adult ward overnight, so you may need to argue a case for staying with your young person. You could also ask if it's possible for your young person to have a side room, rather than be in the main ward.

In these situations, a **hospital passport** is very helpful. Each hospital should have a learning disability team, so asking them for support can also be a good place to start.

Be prepared that the healthcare professionals you're referred to in adult services might not be particularly knowledgeable about Dravet Syndrome. So don't be afraid to share your expertise and knowledge as a parent or carer to advocate for the needs of your young person.

Remember you can signpost to Dravet Syndrome UK. We have information specifically aimed at healthcare professionals, including leaflets, website information, educational events and more.

Practical tip: Get together a hospital passport.

A hospital passport is a document containing important information about someone that you can give to healthcare staff. It can include everything from how they take medication to the fact that you will probably be staying with them and need a chair bed to sleep on.

It can also contain information about Dravet Syndrome. This is helpful because you might need to repeat your young person's story when you meet medical professionals in adult services who may not know as much about Dravet Syndrome.

Download this template hospital passport: **www.togetherforshortlives.org.uk/resource/editable-hospital-passport-template**

Practical tip: Download the NHS app.

If you already have the NHS app for your own healthcare, you can add your young person's profile to yours. You'll need to set up 'proxy access', also known as a 'linked profile'. It needs to be set up by a GP surgery where you and your young person are both registered. There's more information here: **www.nhs.uk/nhs-app/nhs-app-help-and-support/linked-profiles-in-the-nhs-app**

The app only gives a snapshot of their medication and test results, rather than exhaustive information, but it can still be useful to have this information at your fingertips. If you want to check this information, or go into more details, speak to your GP.

Getting started – suggested questions and practical guidance

There are different professionals involved in the transition from child to adult healthcare services, and it's a varied process. So our advice is to start by asking questions and finding out more about your local situation. It's a good idea to start this process around the age of 13, in line with the recommended NHS guidelines listed on page 13 of this guide.

Make a list of all the healthcare services your young person uses along with who is responsible for delivering them. Ask those teams and professionals what steps there are for transitioning to adult services. Be prepared to ask your questions more than once and be persistent if you don't get answers at first.

Below are key questions to ask health professionals involved in your young person's care.

You'll probably have more, depending on the individual needs of your young person, so use this list as a starting point and add more as you think of them:

- What is the plan for transitioning my young person from child to adult healthcare services?
- When will the transition happen?
- Will my young person's healthcare change and in what ways?
- When can we first meet to discuss how their care will look?
- Who will be in my young person's new healthcare team?
- Where will we go for appointments and care?
- Can my young person meet their adult nurse specialist? Will they be our main point of contact with adult services?
- Can we meet the adult learning disability team?
- Who should I speak to about continuing the therapies that my young person has now? How do I find out if equivalent adult therapies are available?
- Will my young person's prescriptions stay the same? Will the suppliers for things like incontinence pads or gastro feeding equipment stay the same?

Talk to professionals at your young person's education services

Remember to discuss transition with professionals at your young person's education services. If your young person's education ends before they are 25, the therapies, nursing and healthcare that they get through their school or college will also come to an end. So, you will need to discuss with them how to get equivalent adult services put in place. This may take some time so should be explored early, around the same time as you start conversations with your healthcare team.

Ideally, these conversations should be coordinated, with the support of your 'named worker' but you may need to take control to start the process moving and to keep it on track. (See page 21 for more on the impact of transitioning to adult services on Education, Health and Care Plans.)

Ask for a joint meeting with your child and adult neurologists

When the time of transition is approaching, ask for a meeting with both your current child neurologist or paediatrician and the adult neurologist. This is sometimes called a 'transition clinic' and can be very helpful in exchanging important medical information through a discussion rather than relying on handover notes. If it's not possible to do this, which it may not be in many areas, ask for a similar meeting which includes your child nurse specialist and adult nurse specialist.

If this doesn't happen, you could contact your local Integrated Care Board (ICB) to request that it does (see **www.nhs.uk/nhs-services/find-your-local-integrated-care-board**)

Have a conversation about medication and prescriptions

Sometimes, accessing certain medicines can be more difficult when a young person with Dravet Syndrome turns 18. This can be for a variety of reasons, including how knowledgeable the adult neurologist is about Dravet Syndrome. It's important to be proactive by asking, in advance, if your young person's medications may be likely to change, and, if so, how to address this. For example, you could ask your child neurologist to write a letter to explain why it's important for prescribed medications to stay the same, unless there are medical reasons to change them.

Collate an information pack for adult teams

This can include:

- A copy of the letter diagnosing your young person
- A letter from their child neurologist with their current medication on it
- Their medical history
- The type of seizures that they have
- A seizure diary, if you have one

You could also include some leaflets from Dravet Syndrome UK explaining the condition.

Transition of social care and other support

The move from child to adult services brings significant changes to the way care and support for your young person living with Dravet Syndrome is managed and funded. When it comes to social care, there's no automatic overlap between child and adult services, so you will need to reapply for care and support packages.

In the UK, all children and young people with epilepsy should have a designated 'named worker' responsible for initiating and planning for the transition into adult services. This is often a social worker and will probably be called something like a 'key worker' or 'transition coordinator'.

Your local authority might contact you first about your named worker. But you can ask your local authority for a named worker when you think that you need one.

Ideally, your named worker should help you to coordinate a transition plan to cover the various aspects of your young person's care. In reality, you may need to be prepared to proactively take the lead. This will involve talking to lots of different professionals across various organisations and systems of care and you may need to repeat your story and your young person's needs often.

Navigating this aspect of the transition of care can seem particularly complicated and challenging. Do ask for guidance and advice from us at Dravet Syndrome UK and the other organisations that we signpost to in this guide. The key thing to remember is that, as someone with complex needs, your young person is legally entitled to appropriate care and support to live a fulfilling life.

This section describes the key elements involved in the transition of care and what you can expect to happen, and also offers some practical tips and insights to help you navigate these systems:

- **Transition assessment**
- **Education, Health and Care Plan**
- **NHS Continuing Healthcare**
- **Funding for adult care packages**

1. Transition assessment

As the parent or carer of a young person with Dravet Syndrome, you're likely already very familiar with the process of a needs assessment. A transition assessment is a needs assessment which starts the planning process for transition.

The purpose of the transition assessment is to make sure there are no gaps in services when a young person reaches the legal age of adulthood and the responsibility of providing care services shifts from children's social care to adult social care.

The assessment is informed by looking at the support your young person needs to live the life they want after they turn 18. It may have goals around further education, living options, social life and health and welfare.

There is no fixed period or age when the transition assessment must be conducted, however it should be carried out within 'a reasonable timescale' before the age of 18. Legally, local authorities must continue providing children's services until they have made a decision about the young person's need for support from adult services.

The transition assessment process varies by region

In **England**, the Care Act 2014 states that before a young person with significant needs turns 18, the local authority must conduct a needs assessment if it considers there is significant benefit to the individual in doing so. You can apply here: **www.gov.uk/apply-needs-assessment-social-services**

In **Wales**, the social care process comes under the Social Services and Well-being (Wales) Act 2014. A similar assessment of needs is made according to a National Assessment and Eligibility Tool. Find out more here: **www.gov.wales/sites/default/files/publications/2019-05/part-3-code-of-practice-assessing-the-needs-of-individuals.pdf**

In **Scotland**, a care needs assessment is arranged by the social care department at your local council. Find out more from the Care Information Scotland website: **www.careinfoscotland.scot/topics/how-to-get-care-services**

In **Northern Ireland**, a health and social care assessment is made with the social services department of your local trust. Find out more here: **www.nidirect.gov.uk/articles/arranging-health-and-social-care#toc-0**

Practical tips for the transition assessment

- Start early (around the age of 13) and be proactive. Be prepared to get in touch with your local authority, rather than waiting for them to contact you.
- Build relationships with the adult social care team as early as possible.
- Be ready to share information about Dravet Syndrome. Professionals in adult services are less likely to be familiar with the condition. Visit the Dravet Syndrome UK website for resources to help with this, including leaflets and template letters.
- Keep hold of all documents and emails and make notes of all your conversations.
- Communicate with your social care team regularly and keep everyone involved in the loop with updates.
- Ask for deadlines. If people are not meeting these, be prepared to chase them up.
- Read what you can to help you prepare for conversations and assessments. For example, the Care Act 2014 and the Mental Capacity Act.
- Ask other parents of young people with complex needs to share their experiences or advice about the transition assessment. You could do this through the Dravet Syndrome UK community. Parents' groups and networks in your local area can also be very valuable sources of information.

Visit the Transition Information Network website, a specialist network of the Council for Disabled Children set up to provide targeted information and resources about transition through online resources and events: **www.councilfordisabledchildren.org.uk/about-us-0/networks/transition-information-network**

The Care Act 2014

Under the Care Act of 2014 (and its equivalents in Scotland, Wales and Northern Ireland), a local authority must conduct a transition assessment where it appears to them that a disabled child is likely to have needs for care and support after they're 18 and it is satisfied that it would be of significant benefit to the young person to do so. The local authority must assess what these needs are likely to be. This duty also applies to the carers of the young person living with a disability.

When they have carried out the transition assessment, the local authority must indicate which care and support needs will meet their eligibility criteria. They must also provide advice and information about what can be done to meet the needs of the young person now and in the future.

The Care Act 2014 is intended to make the transition process easier to understand, including how and when the transition assessment should take place. There are some helpful factsheets available that explain the Care Act 2014 in detail. It's worth looking at these as a starting point:

Factsheet on the UK government website: **www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets**

Factsheet from the Disability Law Service: **www.dls.org.uk/wp-content/uploads/2022/05/Child-to-Adult-Care-Transitional-Assessments-Factsheet.pdf**

Factsheets and template letters relating to the Care Act are available from legal and financial advisors Irwin Mitchell: **www.irwinmitchell.com/personal/protecting-your-rights/factsheets-and-template-letters**

Getting a carer's assessment

A carer's assessment focuses on you as a parent or carer and your needs, wellbeing, health and safety and other commitments, such as employment.

A carer's assessment is free and anyone over 18 can ask for one – including siblings that act as carers. You can ask for a carer's assessment at any time, by contacting your local authority.

There's more information about carer's assessments in the Dravet Syndrome UK *Family Guide*, which you can download here: **www.dravet.org.uk/dsuk-family-guide**

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 them here: **www.cerebra.org.uk/download/letter-to-ask-for-an-assessment-of-needs-for-a-disabled-child-and-carer**

Coordinate your transition assessment with an annual EHCP review where possible

Transition assessments should ideally build on an EHCP, which already contains information about a young person's needs, aspirations and progress towards achieving their outcomes.

You can ask for the transition assessment to be coordinated with an annual EHCP review.

2. Education, Health and Care Plan (EHCP)

Most young people living with Dravet Syndrome in England will already have an EHCP. This sets out the support they will need across education, health and social care services into a single, legal document.

The equivalent to an EHCP in **Northern Ireland** is called a Statement of Special Educational Needs (SSEN). In **Scotland** it's a Co-ordinated Support Plan (CSP). In **Wales** it's an Individual Development Plan (IDP). For the purposes of this guide, we will use the acronym EHCP, but the advice can be applied to equivalent systems.

If your young person already has an EHCP or equivalent, it will have an important role to play in mapping out the transition journey.

The annual EHCP review when your young person is around 13 years old, or in year 9, is a good time to start thinking about transition. This could include thinking about the long-term plans and personal goals (described as 'outcomes' in EHCP terminology) for your child as they prepare for adulthood and discussing these with health and social care professionals.

These outcomes should be realistic, in line with your child's mental capacity, but also continue to identify any opportunities for learning – this will help avoid a situation where a local authority ends an EHCP too early.

Practical tip: Ask your healthcare team about getting a neuropsychology report.

Neuropsychological testing measures reading, language use, attention, learning, processing speed, reasoning, remembering and problem-solving, as well as mood and behaviour. This is useful as it will help demonstrate your young person's mental capacity (see page 8) and help clarify continued learning opportunities that can be reflected in your EHCP. The process involves completing a number of different cognitive tasks and questionnaires.

> **“When my daughter turned 18, the neuropsychology assessment she had was absolutely fundamental in writing the outcomes pertaining to her needs for the future in her EHCP. The psychologist will write a substantial report and you can ask for the EHCP outcomes to be written around what it has found.”**
>
> Mum to young adult with Dravet Syndrome

Planning beyond the EHCP

An EHCP will end when a young person turns 25. It can also end earlier – for example, when a young person either leaves education or has met all the outcomes in their EHCP. You may have to prove that a young person is still in education to make sure they still have an EHCP in place until they're 25.

When it's time for your young person's EHCP to end, their final review should discuss what happens next – with clear timescales, responsibilities and signposting on where to go for more advice. It should explore their aspirations and abilities, what they want to do when they leave education, and the support they will need to prepare them for adulthood.

Once the EHCP funding finishes, then responsibility for funding care, further education or living options moves to either social care, NHS Continuing Healthcare (CHC) or a combination of both.

> **“Just because education ends, doesn't mean your young person has to stop learning and doing things. Have a look at what's available locally that your young person might be interested in. It could be a class, workshop or volunteering opportunity.”**
>
> Mum to a young person with Dravet Syndrome

For information on what to do if your local authority ends your EHCP earlier than you'd like, go to: **www.ipsea.org.uk/if-your-la-takes-away-your-ehc-plan**

3. NHS Continuing Healthcare (CHC) for adults

Some young people living with Dravet Syndrome will have received NHS Continuing Care for Children and Young People (called Children's Continuing Care in Scotland).

When they are 18, they may qualify for NHS CHC. This is a funded package of care to cover the cost of assessed healthcare (including accommodation) for adults in **England** who have particularly intense, complex or unpredictable care needs.

The CHC system in **Wales** is similar to England's. In **Scotland**, it's called Hospital Based Complex Clinical Care. At the time of writing, CHC services in **Northern Ireland** were limited.

Qualifying for CHC

The criteria for CHC are different to those for Continuing Care for Children and Young People. So even if you are receiving Continuing Care, this does not mean that your young person automatically qualifies for CHC. Despite the similarity in names, they are two different systems.

CHC is not means tested. It's an important package of care to apply for as it can cover up to the full cost of the person's care in their own home, a care home or residential setting.

To qualify for CHC, you have to prove that your young person has a 'primary health need'. This means that their care requirements are primarily for healthcare, rather than social care or personal care, and therefore beyond what a local authority can legally provide.

NHS CHC decision support tool

Decisions on qualifying for CHC are made using a document called *NHS Continuing Healthcare decision support tool:* **www.gov.uk/government/publications/nhs-continuing-healthcare-decision-support-tool**

The application process involves demonstrating high levels of health-related need. With Dravet Syndrome, this may include: managing epilepsy, first aid for seizures, medication, mobility, feeding issues, dysautonomia (conditions that affect the autonomic nervous system), managing challenging behaviour, and more.

Each of these is categorised as a 'care domain' with different levels of need, from 'low' to 'severe' and 'priority'. To receive funding, you're likely to need to demonstrate 'severe' and 'priority' needs across several domains.

Practical tip: Become familiar with the *NHS Continuing Healthcare decision support tool* document before you make your application for CHC.

Health and social care professionals use this document to make assessments. Give some thought to how you describe your young person's needs against each domain. Remember to describe their worst day rather than a normal or good day.

More information on NHS CHC and equivalents

You can find more details about CHC, who's eligible and how to apply on the NHS website: **www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare**

See this NHS factsheet to find out more about the concept of a 'primary health need': **www.proceduresonline.com/trixcms2/media/14946/nhs-chc-guidance-on-primary_health_need-2019pdf.pdf**

Visit Care to be Different, a website dedicated to demystifying CHC funding in England: **www.caretobedifferent.co.uk**

For information about Hospital Based Complex Clinical Care in **Scotland**, see: **www.careinfoscotland.scot/topics/how-to-get-social-care-support/hospital-based-complex-clinical-care**

For information about NHS CHC in **Wales**, see: **www.gov.wales/continuing-nhs-healthcare-chc-information-booklet-individuals-families-and-carers**

You can email Dravet Syndrome UK for support and guidance about CHC assessments at: **info@dravet.org.uk**

> "My advice is to do your homework before you have a meeting about CHC funding. Read the *NHS Continuing Healthcare decision support tool* before you go into the meeting. Then, really drill down into the different 'domains' so that you can argue the case as to how your young person is affected.
>
> It's interesting that there is no 'severe' category for 'altered states of consciousness' which defines seizures. Needs should not be marginalised just because they are successfully managed. Well managed needs are still needs. You need to be prepared to argue your case."
>
> Mum to young adult with Dravet Syndrome

4. Funding for adult care packages

In most cases, adult care packages are either funded via a local authority or by the NHS:

- Social care needs are considered to be the responsibility of the local authority and getting support to meet them is means-tested, with an expectation that your young person would make a financial contribution.
- Health needs are considered to be the responsibility of the NHS and getting support to meet them is not means-tested. This is usually through NHS CHC.

In this section, we explain what happens if funding is disputed, the possibility of joint funding between CHC and social care, and to what extent your young person might be expected to contribute to any means-tested social care funding.

What happens if funding applications are refused?

If someone has complex needs, as with Dravet Syndrome, deciding whether they qualify for CHC or social care support may not be straightforward. For example, someone might not be considered eligible for full CHC funding, yet still have some degree of needs that are beyond the powers of a local authority to meet.

It's not always the case, but it's not unusual for funding applications – whether to social care or CHC – to be refused at first. You might find that the recommendation is that your young person's care should be funded through social care, rather than CHC, or vice versa.

This might be very frustrating and disheartening, but if it happens to you – don't give up. The mantra, '**don't be scared, be prepared**' is important here to get the outcome you need. Be prepared to challenge the decision.

Appealing against a CHC decision

After a full CHC assessment you should receive a decision letter from your Integrated Care Board (ICB) – or a third party acting on their behalf – explaining how the decision was made. The letter should also tell you who to contact if you wish to appeal.

You have six months from the date of that letter to request a review of the decision.

The ICB (or third party) then has three months from the date of your request in which to review the decision and complete a local review.

What are the grounds for appeal?

If you have been through a full assessment for NHS CHC and you disagree with the outcome, you have the right to appeal. Grounds for appeal could include the eligibility decision, the procedures used to make it, or how the CHC criteria have been applied in your case.

How to begin a CHC appeal

The first step is to write to the person or organisation that sent your decision letter. This will usually be the ICB which is responsible for the eligibility decision, or a third party organisation which may have been commissioned to carry out the assessment. In your letter, you should outline your reasons for requesting a review.

Once you have made a written request for an appeal, the ICB should begin a local resolution process. This varies depending on where you live but it often involves an informal meeting between you and the CHC team.

Support for an CHC appeal

Whatever form the next steps take, it will be important to prepare thoroughly. Don't forget to ask for help and guidance if you need it, whether from local organisations and parent groups, from Dravet Syndrome UK, or third party organisations such as Beacon, which gives free independent advice about appealing CHC funding in England: **www.beaconchc.co.uk**

Practical tips for appealing decisions about funding.

- Talk to your named worker and healthcare team to help you build the evidence to support your case.
- Speak to any families living locally who have been through a similar process to see if they can share any insights.
- Contact **info@dravet.org.uk** for further advice and signposting to other organisations that may help.

Jointly funded packages between CHC and social care

The *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care* – July 2022 (Revised) talks about how an ICB and local authority may have an obligation to devise a joint package of health and social care to meet their respective responsibilities for someone's care needs, and share the cost of doing so.

They must tell you which organisation will take the lead in agreeing and managing your young person's care plan, and what contribution each is making towards the jointly funded package of care. For example, the split could be 50% social care and 50% CHC funding. Or social care could provide a higher percentage of funding than CHC or vice versa. This depends on the individual needs of your young person that were identified through the assessment process.

It's important to be aware that this is the ideal, but in times of constrained local authority and NHS budgets, it can be challenging to achieve. However, it's possible and worth pushing to get the outcome that is appropriate for your young person and family.

Download the *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care* – July 2022 (Revised): **www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care**

Contributions towards care – what to expect

When your young person is part of children's services, you don't have to pay towards care. But when they're in adult services, they do have to contribute to their care – how much will depend on where they live.

Before adult services start, the local authority will need to do a financial assessment of your young person. This will determine whether and how much they should contribute to the cost of the support they receive. Their contribution will usually come from their benefits (such as Universal Credit), other funding or income. The cost of their daily living needs can be offset against the costs they are expected to contribute. So take some time to itemise these ahead of the financial assessment.

Practical tip: During the financial assessment, remember to list all your young person's outgoings.

This could include, but is not limited to, the following items:

- Equipment, for example mobility aids and seizure monitors
- Special dietary requirements, such as ketogenic diet food
- Therapies, for example physiotherapy and occupational therapy
- Fuel allowance for attending activities
- Carer's fuel and subsistence costs, for example their lunch if they're out doing an activity with your young person

Advice from parents and carers of young people living with Dravet Syndrome

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> **"Transition can be incredibly challenging for our young people. My advice would be to start planning early and have a clear picture of what you want their future to look like."**

> **"Initially we found the whole idea of transition to adulthood scary, but we found that having a plan and vision of our daughter's future and preparing everything well in advance really helps. Speaking to as many other parents as we can in a similar position to us has provided oodles of great information."**

> **"Transition can feel terribly overwhelming, but preparation is key. Talk to others who have already experienced transition with their child. You will get through it!"**

Adult learning and living options

An important milestone for young people with Dravet Syndrome, as with all young adults, is the decision to attend college, or live away from home in a residential or supported living setting. We know this can be a difficult time for parents and carers.

Often parents and carers feel mixed emotions at the thought of their child being an adult and potentially leaving home. Feelings of grief might come up as you're reminded that your young person has a different type of adult life ahead, compared to others of a similar age.

Finding an education and living situation that provides the best quality of life for your young person can be challenging. It can also take time to be able to trust other people to take the right decisions for your young person. Understanding the options is the first step.

Making the move to adult learning

Young people with Dravet Syndrome can continue in special educational needs (SEN) schools until the age of 16 or 19. They may then go on to SEN college if it's the right option for them. Your local authority is responsible for funding specialist education for young people up to the age of 25.

Education options

Specialist colleges

These offer tailored curricula for young adults with profound and multiple learning disabilities (PMLD). There are both private and state specialist colleges. Many provide residential care and what is usually called a 'waking day' or '24-hour' curriculum.

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 (see page 21). These documents state whether a young person has a need for specialist provision beyond what a day school can offer and, if so, will name a residential placement.

Mainstream colleges

Some mainstream colleges will offer support for disabled students. However, not all will be able to support someone's complex needs. Some specialist colleges help their students to attend courses in mainstream colleges.

Other options

Other options include day centres with educational activities. These will vary greatly depending on where you live.

You'll find more information on education options and can search for specialist colleges at: **www.natspec.org.uk**

> **“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 things having to be on her terms, but they've adapted things to suit her. She has a full sensory timetable and is out every day doing something in the community, which is fabulous and really works for her.”**
>
> Mum to a teenager with Dravet Syndrome

Discover your 'local offer'

Every council has a 'local offer' of support in the local area for young people with special educational needs and disabilities (SEND). This includes education options. The local offer should be available on your local authority's website.

Practical tips for adult learning and living options.

- Start your research early – when your young person is around 13.
- Consider whether staying in education is right for your young person. Is it the best way for them to progress and achieve their goals?
- Check the local offer in your area but remember you may be able to arrange for a specialist college place in a different area.
- Visit as many colleges and educational settings as you can. If possible, take your young person with you.
- Think about practical issues, like travel time, distance and transport options.
- Ask questions about the college's approach to care, safeguarding and skills development as well as facilities (see our tips about living options on page 32).
- Speak to other parents with young people with a learning disability or epilepsy. Ask them to share their experiences of adult education. They may suggest options you hadn't considered.

> I found it hard to start considering alternative living options for my daughter. It felt like a huge milestone, not just for her, but for us as parents. I had to trust new people in her supported living house to understand what she needs and have her best interests at heart. But ultimately, seeing her happy and having new experiences made the tough feelings worthwhile.

Parent of young adult with Dravet Syndrome

Living options

It might feel like there aren't many living options for your young person with Dravet Syndrome. In fact, there are four main living options for young people living with Dravet Syndrome when they become adults:

1. **Supported living or supported housing**. This refers to when people live in their own home or share a home with other people with similar health problems or disabilities. People in supported living have some form of care and help with everyday tasks.

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

2. **Residential care home**. Care homes provide 24-hour care onsite. They vary in size and number of staff, depending on the needs of the residents. Your local authority adult social care department can tell you about residential homes in your area. It's important to be aware that places tend to be very limited – another reason to start your research early. If your young person fits the criteria, the local authority normally funds the residential care home place.

3. **Their own home with carer support**. The home may be rented, or there are several ways people with a learning disability can own a home. For example, they can enter a shared ownership agreement, perhaps with investment from their family, or they can buy a home together with other people. They can also buy a home outright, if they have an inheritance or other money to do this with.

   There's more information about options for buying a home when you have learning disabilities on the Mencap website: **www.mencap.org.uk/advice-and-support/housing/housing-faqs**

4. **The family home**. Having considered the alternatives, you may decide that the best living option for your young person with Dravet Syndrome is to stay with you in the family home. 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 and is available at: **www.nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes/home-adaptations**

If you decide your young person with Dravet Syndrome is going to continue living at home, it's a good idea to plan for when you get older and being a carer becomes more difficult. So, it could be helpful to research residential and supported living options anyway, even if you don't decide to use them now. Ideally, it's best to plan and choose a change in living situation, rather than it being done in an emergency or because of a bereavement.

> Our son is now living in his own home, with 24/7 supported living care, funded by NHS 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 the future. He is our whole lives.

Mum to a young adult with Dravet Syndrome

Questions to ask supported living and residential care providers

- What's your knowledge of Dravet Syndrome?
- What training would your staff receive if a young person with Dravet Syndrome was to live there?
- What's the staff to resident ratio? (You'll want to check it's high enough for your young person's needs.)
- How are your services designed around or adapted to residents' needs and aspirations?
- How will a young person be supported to gain independence, new skills and further qualifications, so they can reach their full potential?
- What social activities are there? How do you make sure people can go out and do the things they enjoy?
- How do staff share information with each other about residents? If you use agency staff, how do they communicate with each other?
- What's your approach to food and nutrition? (This is particularly important if your child has a special diet.)
- What's your safeguarding policy? (Ask to see it and don't be afraid to question it or ask for more information. There's more on safeguarding policies on page 48.)
- What's your night-time care for residents? How many staff are on duty then?
- How do you monitor epilepsy? What risk assessments would you put in place for a young person with epilepsy in the house and when out and about?
- How would you manage conflict or challenging behaviour?
- How would you manage sexual behaviour?

Tips for choosing where someone with Dravet Syndrome might live as an adult.

- As well as considering their care needs, think about how important it is for your young person to develop other skills and be part of a community.
- Contact service providers directly and arrange to visit them. Local authorities will have preferred suppliers. But don't feel you have to go along with what they suggest.
- Find out about a housing provider's expertise and approach to someone with Dravet Syndrome when you visit or speak to them. Put together a list of questions you want to know the answers to – see our suggested questions opposite.
- Sign up for newsletters from different providers. This will give you an idea of what they are like and the kinds of activities they offer.
- Visit as many places as you can. Even a visit to somewhere that ends up being unsuitable can help you clarify your needs. It can also be helpful to have evidence of why somewhere is unsuitable, in case this is the option given to you by your local authority and you want to say no.
- When you're speaking to care providers, describe your young person's worst day rather than their best one. This will help the provider understand the level of care they need.
- Discuss living options with other parents whose children have moved away from the family home, both in your area and further afield.

Financial support

Navigating options for financial support and managing your young person's money can be complicated and vary considerably, depending on where you live.

There are several different ways to support a young person with their finances, including being a court appointed deputy (see page 9 for more information). In this section, we've outlined some of the key sources of funding and benefits to support your young person with their care.

Don't forget that in adult services young people are expected to contribute to the cost of their care. How much will depend on where they live and the type of funding package you have. See page 27 for more information on this and advice on offsetting the contribution they make to their care.

Personal budget and direct payments

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

You can choose to be given money in the form of 'direct payments' to buy services, or they can be organised by the local authority. The advantage of direct payments is that it gives you and your young person more control over how their needs are met.

Some examples of how direct payments can be used include:

- Getting help with personal care
- Support to use leisure facilities
- Help with household tasks

To manage direct payments, you might want to open a bank account for your young person when they turn 16, if you haven't already.

Young people with an EHCP (see page 21) may already have a personal budget to cover education costs. Or you may consider the transition to adult services a good time for them to start receiving their personal budget as a direct payment.

If the person being assessed does not have mental capacity (see page 8), or does have mental capacity but can't manage a direct payment, you can be appointed to manage the direct payment on their behalf. See page 9 for more information about becoming an appointee and other options.

Benefits and grants

Here's an outline of the main benefits a young adult with Dravet Syndrome may be entitled to.

Personal Independence Payment (PIP)

PIP is a tax-free benefit for people aged 16 or over who haven't reached state pension age. PIP can help with the extra costs caused by long term ill-health or a disability.

Carer's Allowance

Carer's Allowance is extra money to help you look after someone with substantial caring needs.

Carer's Credit

You could get Carer's Credit if you're caring for someone for at least 20 hours a week. Carer's Credit helps with gaps in your National Insurance record if you take on caring responsibilities.

Universal Credit

Universal Credit is a payment to help with living costs. It's paid monthly, or twice a month for some people in Scotland. People may be eligible if they're on a low income, out of work or can't work.

More information

- For more information on financial assessments, visit the NHS website: **www.nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/financial-assessment-means-test**
- Benefits and other types of financial support change regularly. For up-to-date information, see:
  - the UK government's website about financial help if you're disabled: **www.gov.uk/financial-help-disabled**
  - advice from the charity Contact about claiming benefits for disabled people: **www.contact.org.uk/practitioners/advice/finance-and-benefits**
  - benefits information from Citizens Advice: **www.citizensadvice.org.uk/benefits**
  - a blog post from law company Renaissance Legal outlining benefits that are available when a disabled child turns 16: **www.renaissancelegal.co.uk/blog/benefits-when-your-disabled-child-turns-16**
- For information on grants, visit the Disability Grants website: **www.disability-grants.org**
- Dravet Syndrome UK provides a range of grants, assistance funds and awards for families living with Dravet Syndrome. Find out more here: **www.dravet.org.uk/apply-for-grants**

Practical tip:
Get your benefit application reviewed.

Get expert advice before you submit any benefit applications. You may find you're turned down for certain financial benefits because you haven't provided enough information in the right way. Always get someone experienced to review your application.

If you can't find anyone, email us for advice at **info@dravet.org.uk**

Wills and trusts

Thinking about what might happen when we die can be uncomfortable, but if you're a parent or carer of a young person 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. This gives you an opportunity to formally set out how your young person should be cared for when you die, as well as protecting their future finances.

There are several different options for creating a trust, such as a 'disabled person's trust' or a 'discretionary trust'. It's important to get expert advice on the best approach.

- The **Mencap** website has a helpful Frequently Asked Questions section on wills and trusts: **www.mencap.org.uk/advice-and-support/wills-and-trusts/wills-and-trusts-frequently-asked-questions**
- 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: **advicefinder.turn2us.org.uk**
- The **Contact** website also provides a helpful overview of wills and trusts, including useful links for more information: **contact.org.uk/help-for-families/information-advice-services/preparing-for-adult-life/wills-trusts**

Getting an independent advocate

In some circumstances, young people living with Dravet Syndrome may need more support to get their views and wishes heard. With the help of an advocate, they can gain control over their lives, may be able to make their own choices about what happens to them, and be as independent as possible. Parents and carers can be advocates.

An advocate might help someone with Dravet Syndrome:

- Access information
- Go to meetings or interviews
- Write letters on their behalf
- Speak for them in situations where they are not, or do not feel able to speak for themselves

What is an Independent Mental Capacity Advocate (IMCA)?

It's important that people living with Dravet Syndrome are able to make decisions within their own mental capacity (see page 8). However, there are some circumstances where they must have someone to act on their behalf.

An IMCA is a specially trained advocate appointed to act on someone's behalf if they lack capacity to make certain decisions for themselves. To have an IMCA, the person must not have previously named someone who could help with a decision or have not made a lasting power of attorney (see page 9).

IMCAs are usually appointed by a local authority or NHS body.

When might someone with Dravet Syndrome have an IMCA?

Someone with Dravet Syndrome would have the legal right to an IMCA in these situations:

- They are 16 or over, lack capacity to make certain decisions and do not have a close family member or person who cares for them who is available to support them
- If they have no one to represent their views and an NHS body or local authority is reviewing or planning to review their accommodation
- If there has been an allegation of abuse and there is no one to represent their views

An IMCA would be consulted to support someone who lacks capacity when:

- An NHS body is proposing to provide serious medical treatment
- An NHS body or local authority is proposing to arrange accommodation (or a change of accommodation) in hospital or a care home
- The person will stay in hospital longer than 28 days or in a care home for more than eight weeks

An IMCA may be instructed to support someone who lacks capacity to make decisions about:

- Care reviews, where no-one else is available to be consulted
- Adult protection cases, whether or not family, friends or others are involved

You'll find more information on IMCAs on the Social Care Institute for Excellence website:
www.scie.org.uk/mca/imca

PART 2

Becoming an adult

Impact on family life

Adjusting to your child becoming an adult can be a difficult time for any parent or carer. It can be particularly tough when they have additional needs.

The challenges of puberty often have a big impact on the whole family – it's no different when the young person has Dravet Syndrome. This period of change can also be a time of reflection, which might bring up difficult feelings for parents and carers. So, it's really important to look after your own mental health.

Emotional and psychological support

Moving from child to adult services can be an emotionally challenging time. Don't be afraid to seek additional support if you need it.

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 is 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): **www.bacp.co.uk/about-therapy/using-our-therapist-directory**; and the UK Council for Psychotherapy (UKCP): **www.psychotherapy.org.uk/find-a-therapist**

UK-wide, mental health charity Mind offers support and information: **www.mind.org.uk**

Supporting siblings

It can be important to offer extra support to siblings as their brother or sister with Dravet Syndrome gets bigger and older. Even older siblings may need your help to understand and navigate their brother's or sister's behaviour – especially mood swings or sexual behaviour. Talk to them and share advice on how to help their sibling act in a way that's socially acceptable and support them to stay safe.

Siblings may be going through their own issues with puberty and adolescence. This can complicate their relationship with their sibling living with Dravet Syndrome. Even as they mature and have a better understanding of the needs of their brother or sister living with Dravet Syndrome, it's still important that they have quality time with their parents or carers.

Be open with them, particularly when you're making decisions that affect the whole family – like where your young person with Dravet Syndrome will live.

Sibling support groups can be helpful for siblings of all ages. Research your area to see what's available locally (try putting 'local support groups for siblings' into Google search). The national charity Sibs, has lots of information aimed at both child and adult siblings, including online support groups specifically for adult siblings. Find out more here: **www.sibs.org.uk/support-for-adult-siblings**

More information

Our **Annual Siblings Awards** has two award categories for siblings from 5-15 years old, and 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**

You can also download our *Family Guide* which has more about support for siblings: **www.dravet.org.uk/dsuk-family-guide**

Puberty and Dravet Syndrome

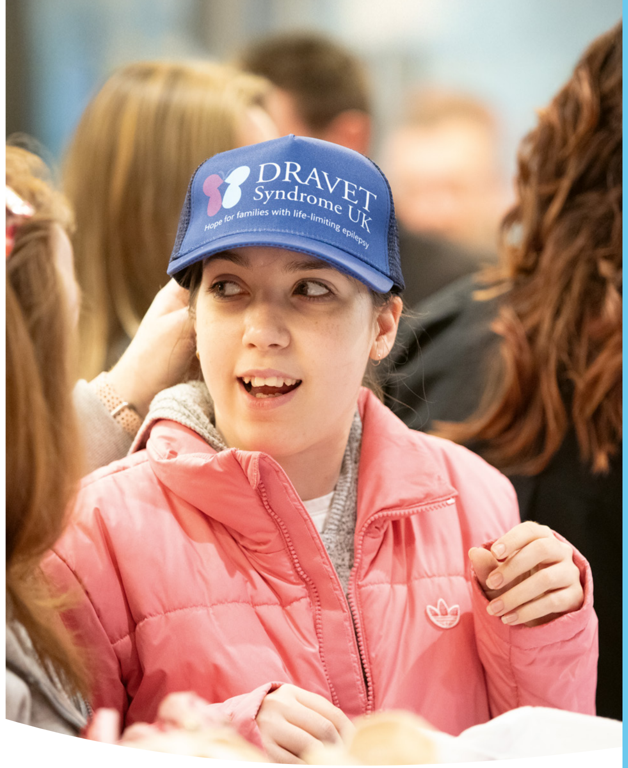
Young people living with Dravet Syndrome will go through all the usual changes of puberty. This includes developing breasts and starting periods for girls and a deeper voice and more muscular appearance for boys. There are some things to be aware of for your young person at this age.

How does puberty affect someone with Dravet Syndrome?

Around adolescence, there are often physical changes in someone with Dravet Syndrome, including with their mobility and seizures. It can sometimes be hard to know which are because of puberty and which are the natural progression of Dravet Syndrome.

The maturing of the body in puberty can have an impact on people with Dravet Syndrome. It can:

- Increase seizures when girls have their periods (see page 42) and if there's a growth spurt for girls and boys. But this is different for everyone and it's not inevitable
- Affect someone's skin, for example teenage acne
- Cause weight gain or loss
- Have an impact on a young person's mobility which might worsen
- Lead to changes in a young person's behaviour due to emerging sexual feelings (see page 43)
- Accentuate co-occurring conditions seen in Dravet Syndrome, for example characteristics of autism and behaviours that challenge



Some people with Dravet Syndrome have early or late onset puberty

The average age for girls to start puberty is 11. For boys, it's 12. When a child has Dravet Syndrome, puberty may come later or earlier than this.

Delayed puberty is when a girl shows no signs of developing breasts, or they have developed breasts but their periods have not started by 15. For a boy, it's when they have no signs of testicular development by the age of 14.

For early or late onset puberty, someone with Dravet Syndrome should be assessed by a paediatrician with experience in this area. Your young person's neurologist or local paediatrician can refer you to the appropriate team.

This is important because, if puberty is accelerated or slowed, it may have an impact on their epilepsy and how this is managed (for example, their medication dosage may need to be reviewed when their height and weight changes).

If you have any concerns about puberty and Dravet Syndrome, raise these with your paediatrician or neurologist.

Periods

Health professionals can support you when your young person starts their periods.

Seizures may increase when someone with Dravet Syndrome has a period – although this is not always the case.

Research has found that seizures during someone's period are mostly caused by physical period symptoms. For example, anaemia, abdominal cramps, changes in bowel habits, headaches, tiredness and fatigue.

To manage this, talk to your young person's neurologist about increasing medication for seizure's during specific points in their cycle. For example, if they take the seizure medication clobazam, an extra dose can be used for a short time. Then it can be reduced back to its usual dose.

Practical tips

- Ask the young person's school nurse, or epilepsy, learning disability or neurology services for guidance on managing their periods. This may include taking contraception to help deal with challenging periods (see page 46).
- Look for signs of period pain or discomfort and give your young person painkillers to help manage this.
- Check with a staff member at your young person's school or college about their policy for supporting girls with periods. They may help manage daily challenges for the young person, such as changing pads.
- Research different ways of managing periods. For example, period pants are like normal underwear but are extra absorbent and can be worn when someone is having their period.
- Keep a diary to see if there is evidence that your young person's periods do have an impact on their seizures.

Sexual behaviour

Most young people experience emerging sexual feelings, needs and desires. Difficult or challenging behaviour can occur if a young person is unable to express their sexuality. It can be hard to talk about this with young people with Dravet Syndrome, but support is available.

Tips for managing sexual behaviour

Talk to your young person about sex. Ideally, this would be before, or when they show signs that they are starting, puberty. It's important to find a way to communicate with your young person about their changing body and sexual desires, especially if they have more mental capacity (see page 8). Discuss inappropriate touching and what to do if someone makes them feel uncomfortable.

Communicate to your young person that they can explore their body in private, but it's not appropriate in public. Plan for what you will do if your young people shows sexualised behaviour in public. This will help you feel ready to manage this if it happens.

Get help from health professionals to discuss sex education with your young person in a way they can understand. Start by talking to your young person's school or community nurse. Ask them if there is a specialist sexual health services for people with learning disabilities in your local area.

Ask your school when and how their sexual education curriculum will be delivered. This National Children's Bureau guidance for SEND teachers on teaching Relationships and Sex Education (RSE) is useful for understanding how this might be covered: **www.sexeducationforum.org.uk/sites/default/files/field/attachment/RSE for disabled pupils and pupils with SEN - SEF.pdf**

Contact your young people's behavioural support service and learning disability team. They can be a great resource for support in this area.

Consider how sexual behaviour will affect others. For example, think about siblings and how to manage what they might witness (see page 39).

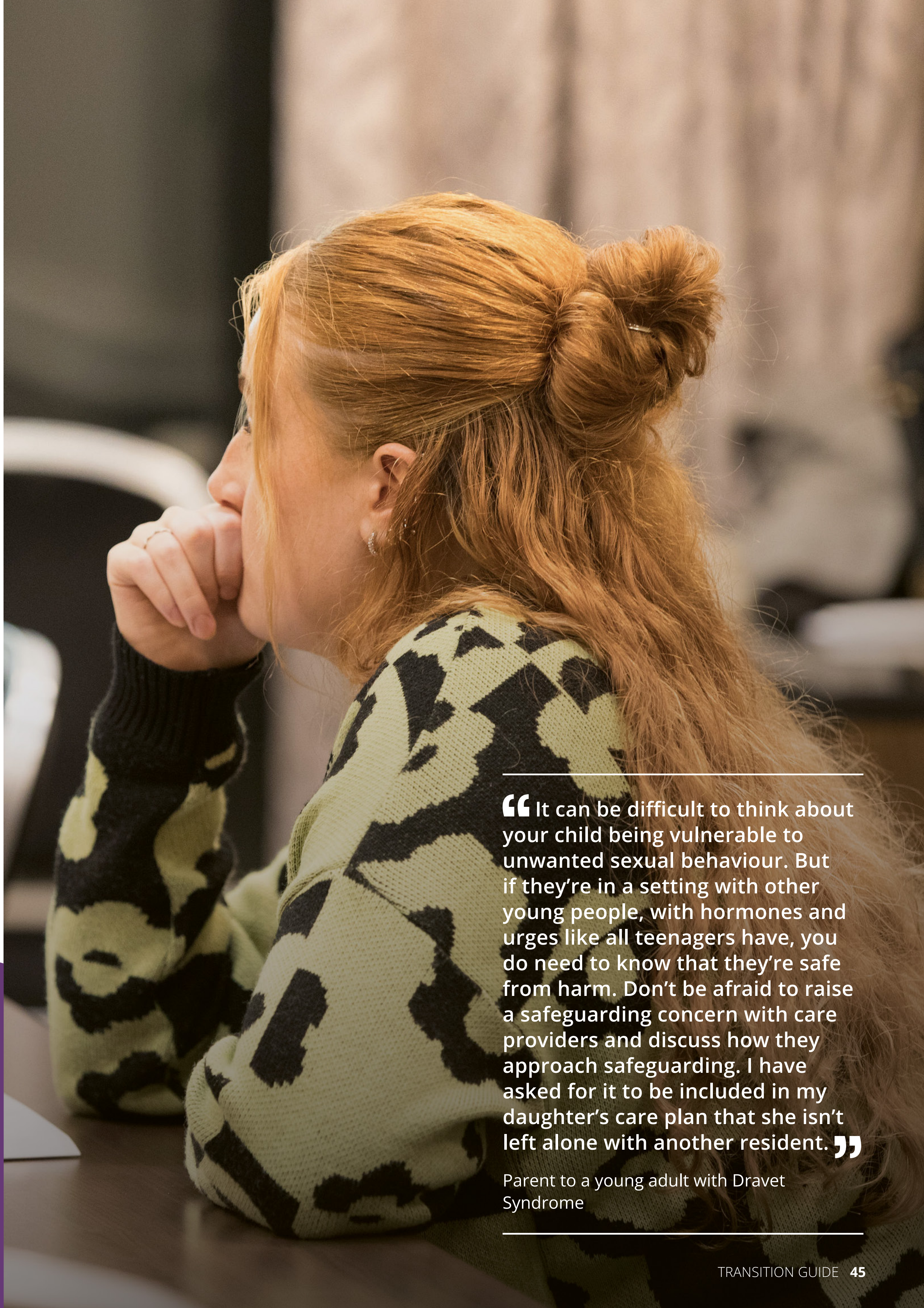
Be open with staff at services that look after your young person. This might feel awkward to talk about but it's important. They should support you with managing the sexual behaviour as they do with other needs.

Ask people involved in caring for your young person to put a care plan in place so everyone knows how to consistently manage any sexual behaviour. If your young person has capacity, they can be involved in these discussions. For example, this might mean checking there's supervision 24 hours a day in mixed sex services.

Ask people involved in caring for your young person if they have had training in managing sexual behaviour. If they haven't had training, you could suggest that they look into introducing this for their team. Adult learning disability nursing teams sometimes run support services for this area of care.

More information

- Download a factsheet on difficult sexual behaviour from the Challenging Behaviour Foundation which supports people with severe learning disabilities: **www.challengingbehaviour.org.uk/wp-content/uploads/2021/02/008-Difficult-sexual-behaviour-.pdf**
- See Mencap's sex education resources and support for people with learning disabilities: **www.mencap.org.uk/advice-and-support/relationships-and-sex**
- There are a range of charities and private companies that can offer support on sexuality and learning disabilities for health and social care professionals. This includes: ARC England: **www.arcengland.org.uk** and the Ann Craft Trust: **www.anncrafttrust.org**



> "It can be difficult to think about your child being vulnerable to unwanted sexual behaviour. But if they're in a setting with other young people, with hormones and urges like all teenagers have, you do need to know that they're safe from harm. Don't be afraid to raise a safeguarding concern with care providers and discuss how they approach safeguarding. I have asked for it to be included in my daughter's care plan that she isn't left alone with another resident."
>
> Parent to a young adult with Dravet Syndrome

Contraception and pregnancy

Girls with Dravet Syndrome may need to use contraception to help manage their periods and so they can continue to take sodium valproate when they are able to get pregnant.

Contraception

Using contraception is one strategy for reducing the impact of, or stopping, periods, especially if they seem to be increasing seizures.

Ask your young person's neurologist or paediatrician about which type of contraception is most appropriate for your young person. Find out which methods could be effective without disturbing their anti-epileptic medications and about those that have the least side effects.

Your neurologist or paediatrician may need to refer you to a gynaecologist.

With the appropriate healthcare professional, you can come up with a plan to trial a type of contraception, being aware that it may have a negative impact on seizures too.

Pregnancy and sodium valproate

Your young person is likely to already be taking sodium valproate. If they are, you will know that two clinicians need to approve the prescription if someone is under 55. This is because the medication is associated with birth defects and developmental disorders in children who've been born to women who take sodium valproate during pregnancy. The drug can also have an impact on a man's fertility.

NICE guidelines say that sodium valproate may only be used in women of childbearing age when all other treatments are not effective or tolerated. So, you might find that an adult neurologist questions the prescription for sodium valproate when you transition to adult services.

The adult neurologist could request that a young women uses contraception if they take sodium valproate. If, as a parent or carer, you can say that there is absolutely no possibility of a pregnancy then a Pregnancy Prevention Programme must be in place. This includes signing an acknowledgement of the risk when their treatment is reviewed by specialists – which should happen at least annually.

More information

- Visit the contraception page of the Choice Support website for guidance on navigating the issue of contraception with your young person: **www.choicesupport.org.uk/about-us/what-we-do/supported-loving/supported-loving-toolkit/contraception**
- See the UK Epilepsy Pregnancy Register, a useful resource for people with epilepsy who are pregnant: **www.epilepsyandpregnancy.co.uk**

Thinking about consent

Contraception

Your young person's involvement in deciding whether they should go on to some form of contraception will depend on their mental capacity (see page 8).

If they have some mental capacity, they will need to be involved in this decision. If the assessment showed that they lack capacity, then you and their neurologist, paediatrician or gynaecologist will need to make a decision in their best interests.

Pregnancy

It's rare for someone with Dravet Syndrome to have the capacity to consent to having sex. This means they don't have the capacity to say 'no' either. This is one reason why thinking about the best way to safeguard them is important (see page 48).

If the person is able to consent to a sexual relationship and there is a risk of pregnancy, they should receive education around contraception, sex and relationships. This needs to be delivered in an accessible way and relevant to their needs.

In Wales, for example, the charity Innovate Trust run peer sexuality and relationship groups for people with learning disabilities: **innovate-trust.org.uk/services/relationship-group-for-people-with-learning-disabilities**

Keeping your young person safe

The vast majority of young people living with Dravet Syndrome are in a safe and supported environment. But it's important to be aware that they can be vulnerable and may need safeguarding support.

There are many ways to communicate and teach personal safety to your young person. How you do this will depend on their level of understanding. Plan what you want to say to your young person and when might be the best time to do so. You might want to revisit the themes of personal safety several times.

For example, you could communicate through:

- Using short sensory stories. Find out more about sensory stories from the Special Education and Inclusive Learning website: **www.inclusiveteach.com/sensory-story-collection**
- The communication tool Makaton
- Easy read guides such as this one from the North Yorkshire Safeguarding Adults Board: **www.safeguardingadults.co.uk/keeping-safe/easy-read-guides**

What makes a good safeguarding policy?

The Care Quality Commission defines safeguarding as "protecting people's health, wellbeing and human rights, and enabling them to live free from harm, abuse and neglect".

When you're looking at living options for your young person, ask to see their safeguarding policy. This is a statement which makes it clear what they will do to keep your young person safe.

It should set out:

- The organisation's commitment to protecting all the people in their care
- The more detailed policies and procedures the organisation will put in place to keep the people they care for safe and respond to safeguarding concerns
- How staff should respond to concerns about allegations of harm to the people they care for
- How the organisation will make sure they recruit the right staff to work with the people they care for
- How staff are prepared to spot and respond to safeguarding concerns
- Multiple ways that staff and the people they care for can disclose concerns
- That everyone, including employees, can be vulnerable and need safeguarding
- How staff should receive regular appropriate safeguarding training
- That staff will be informed of local safeguarding changes and practices and contemporary safeguarding issues

> **"Child protection and safeguarding vulnerable adults is everyone's business. It's challenging to go ahead and report any concerns but the child and vulnerable young adult should always come first as they often have no means to gain help for themselves, much better to make people aware."**
>
> Neil Williamson, Safeguarding Trustee, Dravet Syndrome UK and Children's Epilepsy Nurse Specialist

More information

- If you have any concerns that a young person you know may be at risk, please contact their local area safeguarding team or social care team who will be able to give you advice.
- If you have concerns about a care home, home care agency or other adult social care service, you should contact the relevant local council. You can also contact the Care Quality Commission using this form: **www.cqc.org.uk/give-feedback-on-care?referer=contactus**
- You can call the NSPCC for advice at any time on **0808 800 5000** or email: **help@NSPCC.org.uk**
- For information about different types of abuse, visit the NSPCC website: **www.nspcc.org.uk/what-is-child-abuse/types-of-abuse**
- The NSPCC also has various online and face to face trainings in safeguarding: **learning.nspcc.org.uk/training**
- Read the NICE guidelines on safeguarding adults in care homes. They contain information about the safeguarding process and policy recommendations: **www.nice.org.uk/guidance/NG189**

Key points and helpful links

We hope this Dravet Syndrome UK guide is a useful companion throughout your transition journey from child to adult services.

As mentioned earlier in the guide, everyone's transition journey is different. Yours will vary depending on where you live, your individual situation and many other factors. But this doesn't mean that you and your family are alone.

This final section includes the most important points to remember for parents or carers of a young person who is living with Dravet Syndrome and approaching adulthood.

We've shared links to other useful resources and checklists to support you as your young person moves from child to adult services.

✉ Most importantly, don't forget to ask for help if you need it. At Dravet Syndrome UK, we're always here to advise and support. Email us at: **info@dravet.org.uk**

Essential points for your young person's transition from child to adult services

- Ideally, **the transition from child to adult services should begin when your young person reaches the age of 13**. They should be supported by a named worker (see page 18) whose role it is to consider what support they will need.
- **As a parent or carer, you should be supported through these changes**. Your local authority has a duty to help prevent your own needs from escalating so that you can continue your caring responsibilities, if you want to.
- **Make sure a transition assessment (see page 19) takes place**. A care package should be put in place for your child to ensure all their physical, social and emotional care needs will be met. There should be no gaps in services for your young person during their transition from child to adult social care and/or NHS Continuing Healthcare services. These services should be tailored to their needs as a young adult. Your young person's named worker should make sure that this is the case.
- **Check with each service provider when the transfer from child to adult services will take place**. Ask them who the key contact will be to introduce the new service.
- It's important to **remember that any benefits your child has been eligible for are likely to change as they become an adult** (see page 33). You may need to make arrangements to manage their affairs on their behalf (see page 9).
- **Always try to keep a record of communications about your young person**. This will be helpful if you need to prove anything about their support needs in the future.
- **Remember you can make a complaint and challenge a decision** if you're not happy with it (see page 25). See this guidance from the charity Carers UK on complaining about care services: **www.carersuk.org/help-and-advice/practical-support/arranging-care-and-support-for-someone/making-complaints**

Further information

Local authorities publish information about the transition from child to adult services. Check your local council website for details.

There are also various checklists and guides that provide further details and advice. Here's a selection that you might find helpful:

- UK children's charity **Together for Short Lives** provides a checklist setting out key goals through various phases of the transition from child to adult services: **www.togetherforshortlives.org.uk/app/uploads/2018/03/18-03-20-A-checklist-to-a-good-transition.pdf**
- **Dimensions UK**, a charity that supports families living with learning disability and autism, has a checklist summarising key steps: **www.dimensions-uk.org/wp-content/uploads/Transitions-checklist-2-page.pdf**
- **My Adult – Still My Child** is a useful website for parents or carers of young people who may lack capacity to make decisions: **www.myadultstillmychild.co.uk**
- **Scope** offers an online summary about planning for transition to adult care: **www.scope.org.uk/advice-and-support/planning-transition-to-adult-care-services**

> “Initially we found the whole idea of transition to adulthood scary, but we found having a plan and vision of our daughter’s future and preparing everything well in advance really helps. Speaking to as many other parents as we can in a similar position to us has provided oodles of great information.”

DRAVET
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Hope for families with life-limiting epilepsy

Dedicated to improving the lives of people affected by Dravet Syndrome through support, education and research.

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