



DRAVET Syndrome UK

Hope for families with life-limiting epilepsy



Transition Guide



A guide to
help parents
and guardians
of children
with Dravet
syndrome
prepare for
and manage
the challenges
of transitioning
into adulthood

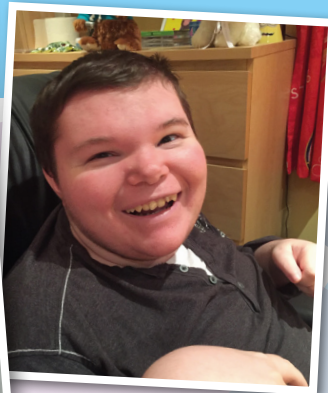
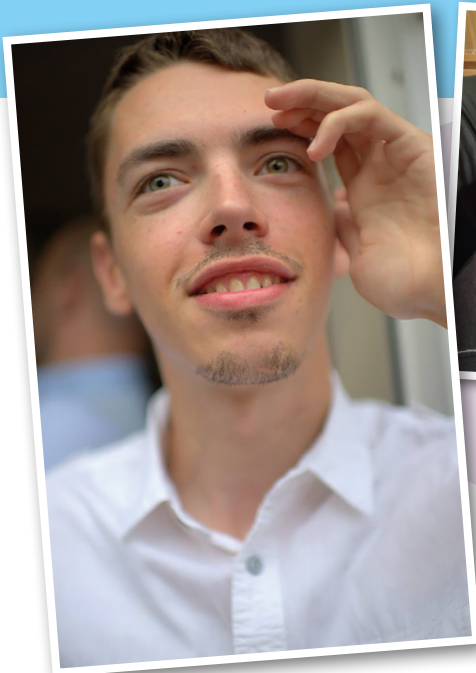
CONTENTS	Page
Preparing for Transition	3
PART ONE: GUIDING YOUR JOURNEY FROM CHILD TO ADULT SERVICES: A ROADMAP	4
1 Legal Deputyship	4
2 Social Care	5
3 Medical Care	6
4 NHS Continuing Healthcare	7
5 Educational and Residential Care	8
6 Financial Support	9
7 Advocacy – Independent Support	10
PART TWO: THE IMPACT OF TRANSITION ON FAMILY LIFE: INSIGHTS AND ADVICE FROM PARENTS	11
1 A Transition in Symptoms	11
2 Monthly Periods	12
3 Emerging Sexual Behaviour and Sex Education	13
4 Supporting Siblings	13
5 Safeguarding in Perspective	14

Preparing for Transition

Transitioning to adult services, when a young person with Dravet syndrome reaches the age of 16 and beyond, can be a very unsettling process for many families. It encompasses significant changes in the organisation of care for your child, touching on all aspects of life with Dravet syndrome – including medical and social care, education, finance and legal rights.

Preparing for transition **in respect of education and social care** should begin at the time of the Year 9 review (when a young person reaches the age of 13–14). This might sound early, but it is important not to underestimate the time and effort involved. Being prepared with accurate information as early in the process as possible, is essential to navigating the challenges of transition. This guide has been put together to help you do just that.

The first part is a roadmap setting out the most important steps in the transition into adult services. It explains the jargon in straightforward terms, provides helpful information and links to further resources. The second part looks at the potential impact of transition on family life and provides practical advice from parents who have experienced this first hand and from experts in caring for young people with Dravet syndrome.



DRAVET
Syndrome UK

Hope for families with life-limiting epilepsy

PART ONE: GUIDING YOUR JOURNEY FROM CHILD TO ADULT SERVICES: A ROADMAP

1 Legal Deputyship

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

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

If deputyship is not obtained, legal responsibility for the young person with Dravet syndrome will no longer automatically rest with you. The local authority will be entitled to take decisions with which you may disagree and you will not necessarily have the ultimate say in decisions involving your child.

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

- In England and Wales, you can apply to be just one type of deputy or both here: www.gov.uk/become-deputy/overview
- In Scotland, you can apply for guardianship here: www.publicguardian-scotland.gov.uk/guardianship-orders/applications/how-to-apply. There are also some useful case studies provided by the Office of the Public Guardian here: www.publicguardian-scotland.gov.uk/general/what-we-do/what-service-do-i-need#Case studies
- In Northern Ireland, you can apply for legal rights to be 'Controller' for a person incapable of looking after their property and affairs (including health and medical care) here: www.courtsni.gov.uk/en-GB/Services/OCP/how-2-become-controller/Pages/default.aspx
- Applications can take a long time (i.e. more than two years and up to four) so make sure you start this process well before your child reaches 18 years of age.
- A case study with insights from one mother's experience of applying for deputyship can be found here: www.dravet.org.uk/about/meet-the-families/their-stories/matthew-williams

2 Social Care

A young person with Dravet syndrome is on a spectrum of need and will therefore require a level of support throughout their life. In our experience, parents/guardians of young people with Dravet syndrome tend to be at the front line, leading and proactively driving care, with varying degrees of support from other professionals. Social care is one of the most important services for parents/guardians, as it is often the service responsible for liaising with, signposting and coordinating professional care from across multidisciplinary services.

Social care is not just about child protection or safeguarding. Social services are there to help people with needs to have a better quality of life and to be able to cope with a complex family life. They have a duty to provide proactive support services to adults who meet their eligibility requirements, and those who care for them.

- If the young person/or adult carer needs a range of services, and is eligible, according to local criteria, social services will put together a package of support which may include services from private or voluntary organisations.
- Carers can ask for a separate assessment of their own needs as a carer, if they feel they are impacted by the burden of caring for another person.
- People who are supported by social care may have to pay towards the cost of some of the services depending on their financial situation.

The social care 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. This needs assessment should be undertaken regardless of whether the young person (or adult carer) currently receives any services. You can apply here:
www.gov.uk/apply-needs-assessment-social-services
- In **Wales**, the social care process is specified 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:
<http://gov.wales/topics/health/socialcare/?lang=en>
- In **Scotland**, a needs assessment is arranged by the social care department at your local council according to National Eligibility Criteria. 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

3 Medical Care

The transition from paediatric to adult care can be challenging for several reasons. Few adult neurologists know much about Dravet syndrome, whilst access to multidisciplinary services and supporting resources becomes even more difficult for physicians to obtain. The transfer of records from paediatric to adult care is often suboptimal. In some cases, it can take years to get hold of past records to find out what treatments and procedures have (and have not) been done.

Accessing unusual medicines may also become more difficult when a young person with Dravet syndrome turns 18. For example, they may no longer be a candidate for trial drugs (such as CBD, or fenfluramine). Depending on location, the ages of 17–18 can be especially difficult to manage. A lack of joined up thinking between paediatric and adult care means that children sometimes are having to be discharged from paediatric care at 17, and cannot access adult care until 18.

The legal position

In England, your local Clinical Commissioning Group (CCG) is responsible for making the provisions for support as specified and quantified in sections C and G of the Education, Health and Care (EHC) plans that are put in place to support children and young people with special needs, under section s42 of the Children and Families Act 2014. If this provision is not made upon transition, it may be possible to seek to complain or judicially review the failure to put such provision in place. (Note that the provision is for health, which relates to, but cannot be seen as educational provision).

The good news is that the more proactive you can be as a parent/guardian, the smoother the transition of medical care is likely to be. Like all changes, the ideal transition is best started early. Plan ahead, ask questions, seek appropriate referrals and arm yourself with information.

When the young person with Dravet syndrome turns 14 years of age start asking the following questions to all professionals:

- What is going to happen when my child/I am moved into adult services?
- Where will this be?
- Do you have a system for this?
- When can we first meet to discuss how their/my care will look?

This approach works well for all professionals and often plants a seed for them – reminding them to start thinking about the transition of this young person and what that will look like.

- As a young person goes through puberty, and ages, the medical picture can change. There is no typical rule for this – it happens at different rates for different people. Be aware of changes in swallowing, walking, seizure types and frequencies and raise these changes with your paediatrician or neurologist.
- Don't forget to link-in educational services. For those young people in special education schools there is a tendency to think “it's ok, they are at school until 19/21...” But when school ends all the therapies, nursing and medical care associated with school support systems ends. There will need to be adult services ready to begin work, so it's important to ensure all school services are considered.

4 **NHS Continuing Healthcare**

Adult Continuing Healthcare is a package of care that is arranged and funded solely by the NHS when an individual, aged 18 or over, has been found to have a 'primary health need'. In the context of Dravet syndrome, this may include managing epilepsy, first aid for seizures, medication, mobility, feeding issues, managing challenging behaviour and many other potential health needs. Care may be provided in the person's own home, a care home or other residential settings, depending on circumstances.

- To access this package of care, the first step is to ask a professional, who is involved in the young person's care, if they feel that Continuing Healthcare may be appropriate for this individual. Social workers and General Practitioners are well-placed to answer this question and either signpost to the local service or support the young person or parents/guardians making an initial referral.
- If requested by social services, your Clinical Commissioning Group (CCG), or equivalent body in Scotland, Wales and Northern Ireland, has to carry out at the very least a screening assessment to see if your child may be someone who could be eligible.
- The CCG will then carry out a full assessment to decide if your child qualifies – this can and should involve input from relevant clinicians involved in your child's care.
- If the young person is found to be eligible for Continuing Healthcare, the person who completed the initial assessment will arrange a full, up-to-date assessment of all care needs.



- The full assessment will be carried out by a multidisciplinary team made up of a minimum of two different health or care professionals, who are already involved in the young person's care, to build an overall picture of needs. In some cases, more detailed specialist assessments may be required from other professionals.
- The full assessment will be taken to a panel that will approve the package of care or ask for more information, or offer what they feel is appropriate. This decision can be appealed.
- NHS Continuing Healthcare is free, unlike social and community care services provided by local authorities, where a young person may be charged for these depending on their financial situation.
- Continuing eligibility for NHS Continuing Healthcare will be reviewed regularly. If care needs change, the funding arrangements may also change.
- You can find out more about NHS Continuing Healthcare here:
www.nhs.uk/chq/Pages/2392.aspx

5 **Educational and Residential Care**

An important milestone for young people with Dravet syndrome, as with all young adults, is the decision to attend school or college, or live away from home in a residential and/or supported living setting. In some cases, a young person may wish to live independently, or it may be felt in their best interests to do so. In other cases, a combination of various factors may mean that a setting other than home is the right move at that time.

There are, at the time of writing, around 60 specialist further education colleges in the UK, most of which offer residential care. However, a place at a college can be very expensive, costing anywhere from £60,000 per year.

Your local authority is responsible for funding places in residential education for children and young people up until the age of 25, if they have an Education, Health and Care (EHC) Plan in England, a Statement of Special Educational Needs (SEN) in Wales or Northern Ireland, or an Assessment of Additional Learning Needs in Scotland.

These documents state whether a young person has a need for specialist provision beyond what a day school can achieve and, if so, will name a residential placement. The placement will be reviewed annually, as part of the annual review of the Plan/Statement/Assessment document.

- Residential settings which care for children for more than 295 days per year or which care primarily for individuals over 18 are regulated by:
 - The Care Quality Commission (CQC) in England www.cqc.org.uk
 - The Social Services Inspectorate in Wales www.cssiw.org.uk
 - The Care Inspectorate in Scotland www.careinspectorate.com
 - The Regulation and Quality Improvement Agency in Northern Ireland www.rqia.org.uk

- Residential settings are assessed on five standards, which ask if the setting is safe, effective, caring, responsive to people's needs and well-led. Check the websites listed above to find out when individual residential settings were last assessed and how they rated against these five standards.

6 Financial Support (Personal Independence Payments & Carer's Allowance)

When a young person with Dravet syndrome turns 16 their disability living allowance will be stopped. They (or their parent/guardian) will be asked to complete an assessment for Personal Independence Payment (PIP), a benefit that helps with the extra costs of a long-term health condition or disability for people aged 16 to 64.

PIP requires a new assessment which is different from Disability Living Allowance. It is not means-tested or subject to tax and it is payable to people who are both in and out of work.

- Claims for PIP are normally started over the phone by calling the PIP new claims number 0800 917 2222 (Text phone: 0800 917 7777).
- Once the claim has been registered, the Department of Work & Pensions will send the claimant a 'How your disability affects you' (PIP2) form for completion, together with an information booklet.
- PIP is assessed on 12 daily living domains and two mobility domains. These include cooking, travelling in the community, personal care and managing medications as examples. They are designed to be proxy assessments for the additional monies that those with disabilities may need in their everyday lives. The more need there is, the higher number of points that are scored.
- PIP has a standard and higher rate for both daily living and mobility which depends upon the score you obtain in the domains above.
- Dravet syndrome can be challenging for PIP assessors. Many professionals categorise Dravet syndrome as a form of epilepsy, when we know the challenges and co-morbidities associated with Dravet syndrome are more complex than this. Therefore, the more information you can provide to assessors about intractable epilepsy and co-morbidities such as autism, ADHD, ataxia, dyspraxia and mobility issues, the better the decision is likely to be.
- There is normally an assessment – either at a person's home or in an assessment centre. You should receive a letter stating where the assessment will take place. You can ask for the assessment to take place in your home if your child cannot realistically be expected to travel to, or cope with, an assessment centre.

The main welfare benefit for carers is called Carer's Allowance and it's worth £62.70 per week (at July 2017). Carers can choose to be paid weekly in advance, every four weeks or every 13 weeks, directly into a bank account. Carers will also be eligible for National Insurance credits each week towards your pension if under pension age.

- You may also be able to apply for support from your local council and a Council Tax Reduction (correct as of March 2017).
- Find out more about carer's allowance here: www.gov.uk/carers-allowance/overview
- Find out more about additional benefits you may be eligible for here: www.gov.uk/browse/benefits/disability

7 Advocacy – Independent Support

Advocacy means to speak up for someone. With the help of an advocate, people with learning disabilities can gain control over their lives, make their own choices about what happens to them and be as independent as possible.

In some circumstances, young people with Dravet syndrome may need more support to get their views and wishes heard.

An independent advocate might help access information that the young person needs, or go with them to meetings or interviews in a supportive role. An advocate can write letters on their behalf, or speak for them in situations where they are not or do not feel able to speak for themselves.

- Health and social services staff both have a duty of care towards those who they are responsible for i.e. they must act in a responsible manner and in the best interests of the individual under the Mental Capacity Act 2005, which means they cannot support anyone in doing something that they think will be bad for them. However, it is important that young people with Dravet syndrome are able to make decisions within their own mental capacity.
- There are certain situations where individuals must have an independent advocate. Firstly, if they are subject to compulsory treatment under the Mental Health Act 1983. In this situation, an Independent Mental Health Advocate (IMHA) will be appointed. Secondly, if they have no family around them, and decisions need to be made about where they live or what medical treatment they receive, an IMCA can be appointed under the Mental Capacity Act 2005.
- You can find out more about advocacy here: www.seap.org.uk/im-looking-for-help-or-support/what-is-advocacy.html



PART TWO: THE IMPACT OF TRANSITION ON FAMILY LIFE: INSIGHTS AND ADVICE FROM PARENTS

Puberty and Dravet Syndrome

Some young people with Dravet syndrome have early or late onset puberty

Puberty is the process of body changes from the first signs of adolescence to full adult development. It is brought about by a series of chemical signals (hormones), sent from the brain to the sex glands, the ovaries in girls and the testes (testicles) in boys. These in turn make the sex hormones, oestrogen in girls and testosterone in boys, which cause the physical changes of puberty.

Normal puberty takes from four to five years in both sexes but starts earlier in girls than in boys. 95% of girls start their periods between the ages of 11 and 15. It is normal for there to be some variation in the age at which puberty starts. Problems most commonly arise through 'mis-timing' of puberty which is either early ('precocious') or delayed. Delayed puberty is a frequent problem but affects boys more often than girls.

When to seek a medical opinion on delayed puberty

If a girl shows no signs of breast development by the age of 13 or no periods by the age of 16, and a boy shows no sign of puberty by the age of 15, they should be assessed by a paediatrician with experience in this area. Your neurologist or local paediatrician can refer you to the appropriate team.

1 A Transition in Symptoms

Be aware that physical, mental and behavioural symptoms may change as a young person with Dravet syndrome goes through puberty and starts to transition into young adulthood.

Seizures may increase during puberty; developmental coordination disorder, or dyspraxia and unsteady gate, may also worsen. Symptoms of autism may become more prevalent. At the same time, the fight for behavioural support can become more difficult as the child gets older.

"We were lucky enough to be assigned to a wonderful psychiatrist at CAMHS, but I do know that isn't always easy, the fight for behavioural support gets harder as they get older. My son has transitioned to the adult mental health team now and is seen every three months. This is ok, but unfortunately we've yet to see the same doctor twice, so continuity of care is hard"

Quote from parent

Helpful advice:

- Keeping a seizure diary, or a good record of when seizures occur, is always the ideal approach, but it can be time-consuming. Two important details to note are:
 - Are there more seizures occurring around menstrual cycles for young women?
 - Are growth spurts and bodily changes in boys and girls coming with increased seizures?
- If puberty is accelerated or slowed this can affect epilepsy and the natural behaviours of Dravet syndrome at different ages. If you have any concerns, raise these with your paediatrician or neurologist and ask them questions about puberty – it will highlight any potential issues and remind them to review these as part of the young person's appointment.



2 Monthly Periods

For girls with Dravet syndrome, starting periods can be particularly distressing for the whole family. Seizures may increase before and during periods. Your GP can provide advice around how to manage monthly periods. This may include taking contraception to help reduce the burden of challenging menstruation. Your GP may also refer you onto expert services in sex education and in managing behaviours relating to emerging sexuality (see below).

"I hate the periods, we will usually see an increase in seizures just before her period each month. I will constantly find used sanitary towels in random places, all over the house. I often hear her younger sister shouting as she has come across a sanitary towel in a draw or somewhere. It really isn't pleasant for any of us"

Quote from parent

Helpful advice:

- Be proactive where possible. Look for signs of period pains and give simple painkillers to help manage discomfort.
- Contraception is one strategy for reducing the impact of, or stopping, monthly periods. Ask your GP about which type of contraception is most appropriate for the young person with Dravet syndrome, i.e. methods which are effective without disturbing anti-epileptic medications and which have the least side effects.
- Check with your school/college as to their policy for supporting girls with periods. They may help manage daily challenges for the young person, such as changing pads etc.

3 Emerging Sexual Behaviour and Sex Education

It can be very challenging to talk about sexuality and related behaviours with young people with Dravet syndrome. All young people experience emerging feelings about sexual needs and desires, and all young people are different. Difficulties can occur if these emerging feelings translate into behaviours where a young person is unable to express themselves or practice their sexuality appropriately.

There are experts who can help discuss sex education issues with vulnerable young people in a way that is pitched at the right level for them to understand. You can access support from these expert services if you want to raise specific questions and/or discuss strategies for helping a young person to find good solutions for challenging behaviours.

- Expert sexual health services are available via Special Educational Needs provisions, such as the school nurse, or by requesting support via your GP.
- The sexual health charity, the Family Planning Association (FPA), also has useful resources and support for people with learning disabilities, which you can access here: www.fpa.org.uk/training-courses/expert-training-and-consultancy-learning-disability-sex-sexuality-relationships
- Don't forget, schools also have sex education on their curriculum. Ask your school when and how this will be delivered. This may help you decide whether you need to go ahead and access additional services.

4 Supporting Siblings

Being a sibling of a child with Dravet syndrome comes with its challenges and its rewards. In the end, all people are different and children need support in different ways. There are often young carers or sibling services, which can be supportive to young people who have a sibling with Dravet syndrome. If a family is attached to a children's hospice, there are often sibling support services that can be accessed there. Universal (non-specialist) groups, such as cubs and scouts or a football team, can also be a great support to siblings.

"Trying to teach him to have some modesty has been hard – he'll happily walk round the house naked and has no issues with his trousers slipping down, we just use gentle reminders (not so gentle when his sister encounters him naked on the landing and she's got a friend staying!) and encourage carers to do the same. He'll agree with us that he will try to remember, then forgets again!"

Quote from parent



Helpful advice:

- For siblings aged 8–17, the ‘Over The Wall’ charity runs sibling residential activity camps for siblings across the UK free of charge. It provides excellent sibling support and is rated ‘outstanding’ by Ofsted. You can apply to join online at www.otw.org.uk
- Schools may often provide pastoral support and help if appropriate and wanted.
- There may be local youth services and mentor programmes to help in your local area. It is worth checking children's centres or looking on the internet for local services.

5 Safeguarding in Perspective

Safeguarding vulnerable young adults is a sensitive issue. The statistics can seem quite scary: people with disabilities are four times as likely to be a victim of sexual abuse and any other crime. The good news is that the vast majority of children/adults with Dravet syndrome are always in a supported environment. Nevertheless, it is important to be aware that these young people are vulnerable.

Helpful advice:

- If you have any concerns that a young person you know with Dravet syndrome may be at risk, please contact their local area safeguarding team or children's social care team who will be able to give advice.
- You can also call the **NSPCC** on **08088005000** for advice at any time and they will help you move any concerns forward appropriately.

“Child protection and safeguarding vulnerable adults is everyone’s business. It is 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”

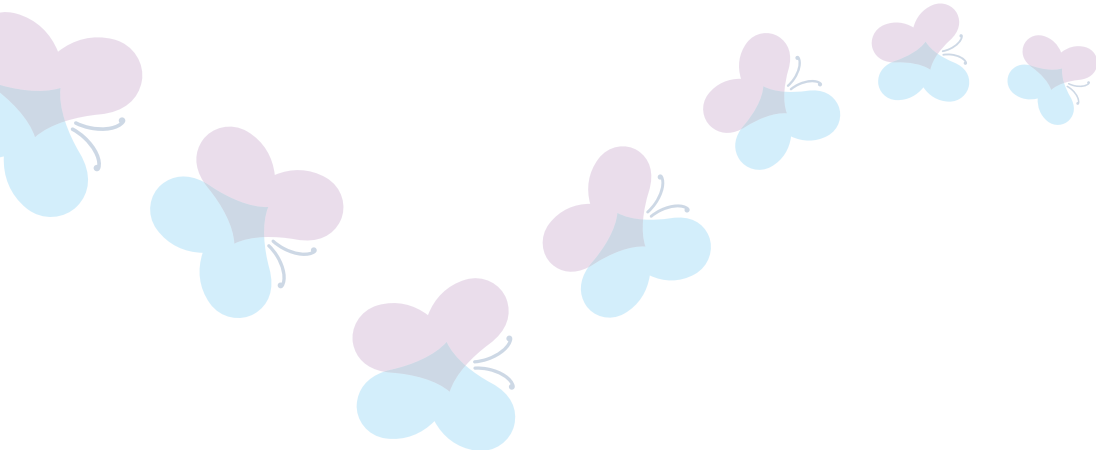
Quote from healthcare professional




This guide has been produced in collaboration with
Neil Williamson, Epilepsy Nurse Specialist
Sanjay Sisodiya, Professor of Neurology & **Fiona Scolding QC**



Hope for families with life-limiting epilepsy



 Facebook **Dravet Syndrome UK**

 Twitter: **@dravetUK**

 LinkedIn: **[linkedin.com/company/10990437](https://www.linkedin.com/company/10990437)**

 YouTube: **DravetSyndromeUK**

Dravet Syndrome UK

PO Box 756,
Chesterfield, S43 9EB

Tel: **07874 866937**