Transition to Adulthood

DOWN'S
SYNDROME
ASSOCIATION

photo by @brianophotography

Applies to England Only.

Please note this guide contains rights-based information, it is not intended as legal advice.

The transition to 'adulthood' or adult services can be a tricky terrain to navigate. For children and young people who may have education, health and social care needs, this transition can involve multiple different 'transitions'. For parents/carers, it is also a time when your role is changing too, as, in law, your young person is now becoming legally entitled to make their own decisions (subject to mental capacity).

We have produced this resource to simplify the process, setting out the timescales and signposting to several Down's Syndrome Association resources that you might find helpful, as well as some resources from other organisations.

Of course, every young person who has Down's syndrome is unique, and this resource can only set out likely timescales. You may find your own young person's journey deviates slightly from this due to their individual abilities and needs. This guide, although comprehensive, will also not include all the decisions that you and your young person will need to make as they transition from children's services to adult services. We have attempted to include the main areas that you need to be aware of.

Unfortunately, we often hear feedback from families where legal processes and timescales are not followed. If you find yourself in this situation, please do contact the Helpline (see below) for advice and support relating to your individual circumstances.

We are here to help you.

If you need individual advice, please do not hesitate to contact us via our Helpline by telephone 0333 121 2300 (10am-4pm) or by email info@downs-syndrome.org.uk

We would be very happy to assist you. However, please be aware that we do not provide legal advice. We provide rights-based information and advice based on a general knowledge of particular areas of law.

Transition Planning

Age 14
Year 9

Start Preparation for Adulthood (PfA) planning at the Year 9 Annual Review meeting (see page 9).

Annual health checks with the GP should commence (see page 12).

Ensure your young person is on the GP practice Learning Disability Register (see page 12).

Age 15
Year 10

Start planning for post-16 education. Visit any possible education providers if your young person’s school finishes at 16 years/end of Year 11 (see page 14).

Schools should be providing careers advice during Year 10.

Your school might arrange the transition annual review in the summer term of Year 10, to allow enough time for the local authority to name the post-16 setting for Year 12.

Transition Planning

Age 16
Year 11

Young people can legally leave school at the end of the school year in which they turn 16 (this is normally at the end of Year 11). However, all young people must be in education or training until the age of 18.

In autumn term of Year 11, apply for a place at your preferred post-16 setting (see page 15).

The EHCP transition annual review should take place in the autumn term of Year 11 if it did not happen in the summer term of Year 10.

6 January in Year 11 is the latest date that the Annual Review meeting should take place (see page 16).

The Local authority must name the post-16 setting by 31 March in Year 11 (see page 16).

Apply for post-16 transport (see page 18).

Transition Planning

Age 16
Year 11

From age 16 there is a presumption in law that people can make their own decisions unless it is proved otherwise. This comes under the provisions of the Mental Capacity Act 2005 (see page 20).

Social care transition planning should start at age 16/17 at the time when there is significant benefit in starting the process (see page 22).

People aged 16 or over are entitled to consent to their own health treatment (see page 25).

When your child reaches 16-years-old, the benefits that they claim and that you claim for them as a dependent, may change (see page 28).

Age 17

If social care transition planning has not yet started, it is likely to be of significant benefit to start when your young person reaches 17 years old (see page 22).

Transition Planning

Age 18

EHCP ❯❯❯ 25

Young people are no longer required to be in education or training. An EHCP can continue until 25 years old, in certain circumstances.

It is important to start planning for post-education provision (see page 31).

Adult social care and provisions under the Care Act 2014 start from age 18 (see page 35).

Adults are presumed to have sufficient mental capacity to decide on their own medical treatment, unless there is significant evidence to suggest otherwise (see page 40).

Once they turn 18, a young person becomes legally responsible for managing their own money (see page 44).

Once a young person reaches 18, they will be included in the council tax calculation (see page 45).

Age 19

Rights to free medical prescriptions end. You can apply for a certificate to help with some or all health costs (see page 42).

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Education – Transition Planning from Year 9/14 Years Old

The Year 9 Education, Health & Care Plan (EHCP) annual review is normally the time when you should formally start 'preparation for adulthood' planning with your young person. Planning must be centred around the individual and explore the child and young person's aspirations and abilities, what they want to be able to do when they leave post-16 education or training and the support they need to achieve their ambition. We have a range of resources and information available on our website to help you at this time.

The SEND Code of Practice (January 2015) states:

Local authorities must ensure that the EHC plan review at Year 9, and every review thereafter, includes a focus on preparing for adulthood. It can be helpful for EHC plan reviews before Year 9 to have this focus too. Planning must be centred around the individual and explore the child or young person's aspirations and abilities, what they want to be able to do when they leave post-16 education or training and the support they need to achieve their ambition.

Local authorities should ensure that children and young people have the support they need (for example, advocates) to participate fully in this planning and make decisions. Transition planning must be built into the revised EHC plan and should result in clear outcomes being agreed that are ambitious and stretching and which will prepare young people for adulthood.

Where it states 'must' this is an absolute legal duty, which means that it is not optional, and the local authority are required to do this in law.

The Year 9 annual review should include the following:

- support to prepare for higher education and/or employment. This should include identifying appropriate post-16 pathways. Training options (eg. supported internships, apprenticeships and traineeships) should be discussed, or support for setting up a business. It should also include support in finding a job, and learning how to do a job, including work experience opportunities and help in understanding any welfare benefits that might be available when in work

- support to prepare for independent living. This should also include discussing where the child or young person wants to live in the future, who they want to live with and what support they will need. Local housing options, support in finding accommodation, housing benefits and social care support should be explained

- support in maintaining good health in adult life, including effective planning with health services of the transition from specialist paediatric services to adult health care, ensuring those professionals understand the young person's learning disability

- support in participating in society, including understanding mobility and transport support, how to find out about social and community activities and opportunities for engagement in local decision-making. This also includes support in developing and maintaining friendships and relationships.

Your young person's EHCP should be updated following the Year 9 annual review meeting to reflect their updated outcomes and the support and provision that they will need to achieve these outcomes.

Young people can legally leave school at the end of the school year in which they turn 16 (this is normally at the end of Year 11). However, all young people must be in education or training until the age of 18. This can include an apprenticeship or traineeship. It can also be combined with paid or voluntary work. Young people entering post-16 education and training should be accessing provision which supports them to build on their achievements at school and which helps them progress towards adulthood.

The SEND Code of Practice states:

> **Where young people have EHC plans, local authorities should consider the need to provide a full package of provision and support across education, health and care that covers five days a week, where that is appropriate to meet the young person's needs.**

This five-day package could include volunteer work, work experience, life skills opportunities and training to enable your young person to develop and maintain friendships and support them to access facilities in the local community. It could also include health and social care related activities. Please note that if health or social care provision 'educates or trains' then it must be classed as special educational provision within an EHCP.

As your young person approaches adulthood, person-centred planning approaches can be helpful. Good support is responsive to the needs and wishes of the individual young person. The level of engagement that will have in planning their support will be different depending on their individual abilities and needs.

Useful Resources:

Easy Read document for young people about transition

Supporting teenagers

Planning for adulthood and transition

Post 16 Planning

Support Planning

Making choices and encouraging independence

NDTI's Preparation for Adulthood tools and resources

SEND Code of Practice (January 2015)

School leaving age

Health – Annual Health Checks from age 14

The move between child and adult health services is likely to be a phased transition between ages 16 and 18. Different services may have different age limits. During this time your son or daughter will move from the care of a paediatrician to oversight by their GP. All adults with learning disabilities have a right to an annual health check from their GP and in April 2014 this was extended to young people age 14-17. The annual health check could be a useful way of the GP getting to know a young person with Down's syndrome better before the formal move to adult health services.

Everyone who has Down's syndrome should be registered on their GP practice Learning Disability Register (LDR). (Note: This is not the same as the Disability Register held by the local authority social care teams). Your child/young person can join the GP's Learning Disability Register at any age. If the GP practice knows a person has additional needs, then they should put reasonable adjustments in place to make sure they get the right healthcare when they need it. Registration is not automatic, so it is a good idea to ask the receptionist at the GP practice to check if your young person is on the LDR. If they are not on the LDR, the receptionist will ask about their needs. This information will be put on the person's Summary Care Record (SCR) so all health professionals at the practice know about their needs and how best to support them.

It is important that everyone over the age of 14 and above is on their GP's Learning Disability Register (LDR) and has their annual health check.

If a person who has Down's syndrome is on their GP's LDR, the GP practice should get in touch to offer an Annual Health Check, but this does not always happen. A person who has Down's syndrome and/or a supporter can ask their GP for the check. Not all GPs do Annual Health Checks for people with learning disabilities, but they should be able to provide details of other GPs in the area who offer this service.

The GP should tell the person who has Down's syndrome what they have found during the Annual Health Check. They should ask if the person has any questions and, if needed, they may refer them to specialist services for further tests. The GP will use what they found during the check to make a Health Action Plan. This should set out the key actions that need to be taken that have been agreed with the young person who has Down's syndrome and (where applicable) their parent/carer.

Useful Resources:

Annual health check

Annual health check checklist for GPs

NHS Annual health checks (including helpful video)

Mencap's Easy Read guide to annual health checks

Planning for Post-16 Education - Year 10/Age 15

From 2015 all young people must stay in education or training until their 18th birthday. Many young people who have Down's syndrome will attend schools that only go up to year 11 (age 16). Some people also choose to move school or go to college at this age.

It is important to plan at least a year ahead for your son or daughter to be leaving school. You should also be aware that many local authorities may only fund post-16 courses on an annual basis, so a two or three year course may not be guaranteed.

During Year 10 we advise you to visit possible post-16 education providers and find out what courses they will have available. You can meet with the college SENCO or Foundation Studies course leader to discuss your young person's aspirations and the support that they might need in a post-16 setting. You can also look at the setting's website for a copy of the setting's SEN Information Report, which will explain the extra support normally available to students with SEND.

During Year 10 your young person should also speak to a careers advisor in school. Schools have a legal duty to provide impartial careers advice to all young people from Year 8 (13-14 years of age) onwards.

During the Year 10 EHCP annual review meeting you should discuss yours and your young person's wishes for post-16 education, so that the local authority are aware of your intentions. You should also request that the adult social care/transition team are invited to attend this annual review meeting.

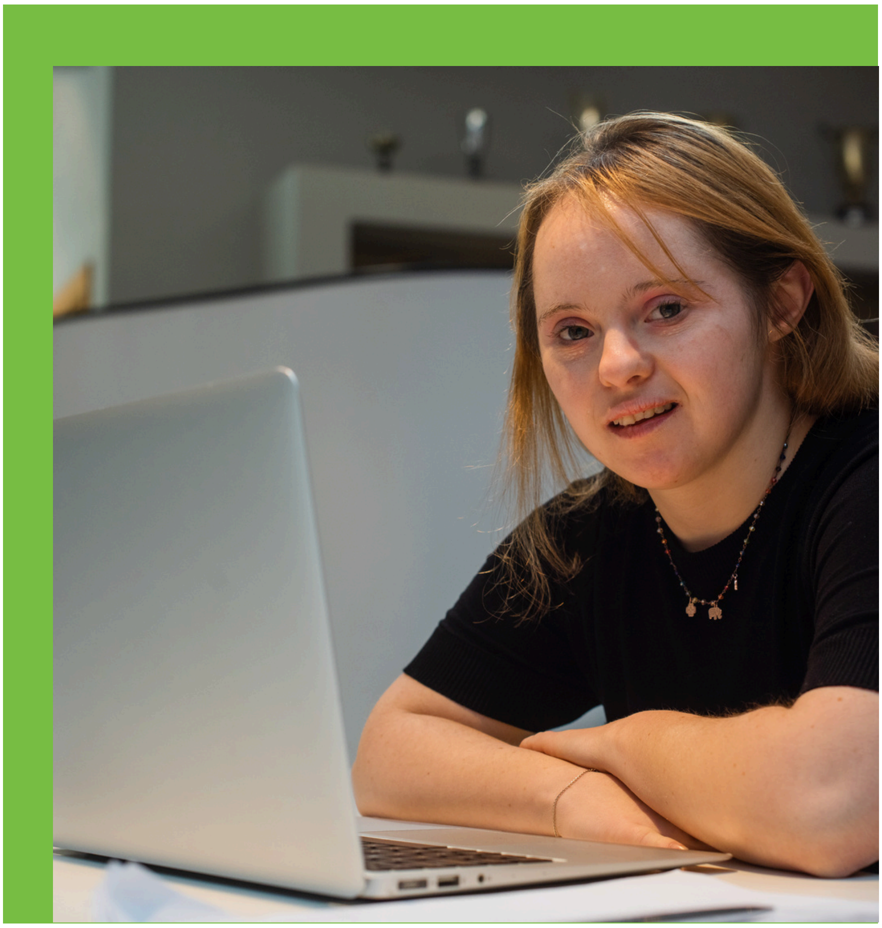
In addition to the Year 10 annual review meeting, there will also need to be a phase transfer review meeting held. This is to discuss and hopefully agree transition to a post-16 setting. This meeting needs to be either in the Summer term of Year 10 or very early in the Autumn term of Year 11. This should allow enough time to appeal if you disagree with the local authority's decision. The post-16 provider and adult social care/transition team should be invited to attend this meeting to start the transition process.

Education – Year 11/Age 16

Young people entering post-16 education and training should be accessing provision which supports them to build on their achievements at school and which helps them progress towards adulthood.

Young people who have Down’s syndrome are likely to need tailored post-16 pathways. As children approach the transition point, schools and colleges should help children and their families with more detailed planning. In Year 11 they should aim to support you and your young person to firm up plans for post-16 options. Schools and colleges should work in partnership to provide opportunities such as taster courses, link programmes and mentoring which enable young people to familiarise themselves with the college environment and gain some experience of college life and study.

In the first term of Year 11 you will need to apply for your young person’s post-16 place if they are changing setting. Further education institutions will have their own applications process that you need to follow. They may invite your young person in for an interview to ensure that the course will be suitable for their individual aspirations, abilities and educational needs. It is important to apply as quickly as possible to your chosen setting, as places on popular courses can be limited.



Some college courses will condense the teaching hours across 3 or 4 days, meaning that your young person is not required to attend on the other days.

The SEND Code of Practice states that:

> **Where young people have EHC plans, local authorities should consider the need to provide a full package of provision and support across education, health and care that covers five days a week, where that is appropriate to meet the young person's needs.**

This package does not have to be at one provider and could involve amounts of time at different providers and in different settings. It may include periods outside education institutions with appropriate support, including time and support for independent study.

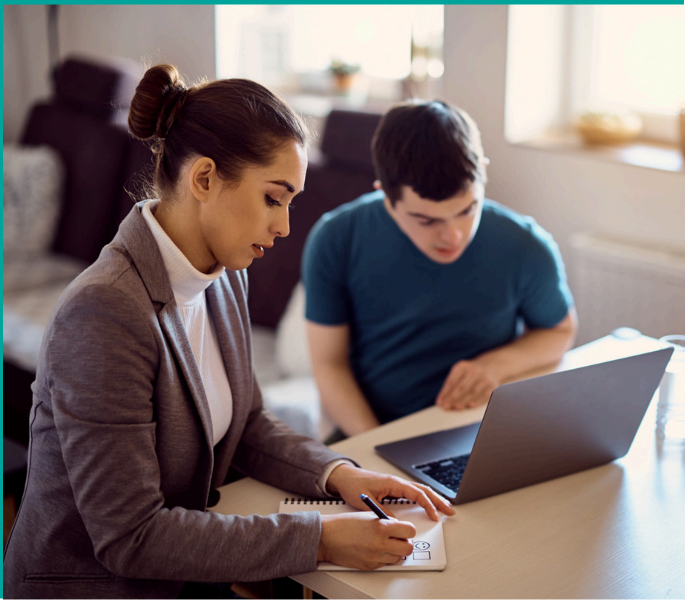
A package of provision can also include non-educational activities such as:

- volunteering or community participation
- work experience
- opportunities that will equip young people with the skills they need to make a successful transition to adulthood, such as independent travel training, and/or skills for living in semi-supported or independent accommodation, and
- training to enable a young person to develop and maintain friendships and/or support for them to access facilities in the local community.

It can also include health and care related activities such as physiotherapy. Full-time packages of provision and support set out in the EHC plan should include any time young people need to access support for their health and social care needs. In making decisions about packages of support, local authorities should consider the impact on the family and the effect this impact is likely to have on the young person's progress.

As well as your application to the post-16 setting, you will need to ensure that the Local authority agrees that the course/package of provision that you are seeking and that any preferred setting(s) can meet your young person's individual needs. This process is undertaken through a transfer review of the EHCP. As previously mentioned, this review should take place in the final term of Year 10, or the first term of Year 11.

6 January in Year 11 is the latest date that the Annual Review meeting should take place to ensure that the local authority can name the post-16 setting by **31 March in Year 11.** This is the statutory deadline that they must adhere to.



The current education setting must provide at least two weeks' notice of the transfer review meeting. As with the usual annual review process, you and your young person will be invited to contribute your views, which will be collated with all the reports and feedback from the professionals involved in your young person's education, health or care. These reports must be sent to you two weeks prior to the date of the meeting, so that you have enough time to read them.

At this stage, your young person's views are considered more widely, and they should be invited to express their preference of post-16 education or training. Where a young person is under 18, the involvement of parents continues to be particularly important and local authorities should continue to involve you in the vast majority of decisions.

The SEND Code of Practice states that:

> **As young people develop, and increasingly form their own views, they should be involved more and more closely in decisions about their own future. After compulsory school age (the end of the academic year in which they turn 16) the right to make requests and decisions under the Children and Families Act 2014 applies to them directly, rather than to their parents. Parents, or other family members, can continue to support young people in making decisions, or act on their behalf, provided that the young person is happy for them to do so, and it is likely that parents will remain closely involved in the great majority of cases.**

After the meeting has taken place, the current education setting should send the review report to the local authority within two weeks. The local authority then has four weeks to issue an updated draft EHCP that reflects the discussions that have taken place. You will be given at least 15 days from the date of the draft EHCP to respond with your comments on the content and to name your preferred placement for phase transfer.

The local authority must consult with all preferences named in the feedback from yourselves and your young person. The local authority must issue the final amended EHCP, naming the placement for phase transfer (or naming the type of placement if a specific placement is yet to be identified) within 8 weeks of the date of draft EHCP. The latest this can happen is 31 March.

If you are unhappy with placement or provision, you can go to mediation or appeal via the SENDIST tribunal. Appeal as soon as possible. **It is important not to delay.** Whilst SENDIST Tribunals take account of the admissions timeline and will try to schedule hearings about placements before the end of Summer Term so that families and young people know where they will be going, there can be a significant period between the appeal application and the date of a hearing.

Once a placement/package has been agreed and confirmed, you and your young person should expect to attend transition meetings to plan for their transition during the summer term of Year 11. Your young person should also be invited to transition visits/welcome days at the new setting, to help them become familiar with the setting. You might find social stories or photo books helpful to support them in preparing for this change.

It is important that information about previous SEN provision is shared with the further education or training provider. Schools should share information before your young person takes up their place, preferably in the spring term prior to the new course, so that the provider can develop a suitable study programme and prepare appropriate support.

If your young person will need transport to get to school/college **please ensure you remember to apply for transport in good time.** The transport needs of young people with special educational needs and disabilities must be reassessed when a young person moves from compulsory schooling to post-16 education, even if the young person is remaining at the same educational setting.

Free transport to post-16 education is not an automatic right, as the transport duties for local authorities are not the same for this age group.

photo by Nadia Bettiga

The 16-19 transport duty applies to young people of sixth form age with special educational needs and disabilities aged up to 19 (and beyond the age of 19 if they are continuing a particular course started before the age of 19).

Transport for 16-19 year olds is discretionary, and local authorities may ask parents for a contribution. You should look for your local authority's Post 16 Transport Policy statement which **must be published on their website by 31 May each year.**

You will be provided with information through the transport policy statement about who is eligible for transport support and how and when you should apply for support. Details of any concessionary fares, discounts, subsidies or travel cards should be included alongside the eligibility criteria for this support and how eligibility will be assessed.

Useful Resources:

Education rights post 16

31 March deadline for transitions

Transition planning

Education Rights Post-16 education

Education: Further Education

Making a transition book

School/College Transport

DfE Post-16 Transport statutory guidance (January 2019)

Decision Making from Age 16

Many parents will already have involved their children in making choices and decisions from an early age. This can start very simply, and more complex choices can be introduced in line with the child's age and ability.

From age 16 there is a presumption in law that people can make their own decisions unless it is proved otherwise. This comes under the provisions of the Mental Capacity Act (2005). It is important to be aware of this Act and to know both how to support your young person to make decisions and how decisions should be made if they lack capacity.

Mental capacity is the ability to make decisions, and it is always assessed on a decision-by-decision basis.

When a person turns 16, under the Mental Capacity Act (2005), the starting point is to assume they have capacity to make decisions for themselves. The law says a person must be given relevant information in an appropriate format and time to understand it before a decision on their capacity is made. This may mean that pictures, symbols, diagrams, videos, sound clips, verbal conversation or other formats that the person normally uses to communicate are used to help the person to understand the options open to them. They might require extra time to be provided, to allow them to understand the decision that is being made, and also that appropriate information and support is provided. This is known as supported decision making.

The Mental Capacity Act (2005) states 'a person's capacity (or lack of capacity) refers specifically to their capacity to make a particular decision at the time it needs to be made'.

Mental capacity must be assessed in relation to every decision that needs to be made, at the time it needs to be made. Therefore, it is not possible to assess overall capacity and make blanket decisions on a person's behalf because at a particular time they were found not to have capacity. For every decision to be made, work must be done, and time given, to support the person to understand the relevant information before it can be determined who the decision maker will be. If your young person can retain and weigh up information and communicate their decision, they are deemed to have the capacity to make the decision for themself.

It is important to be aware that under the Mental Capacity Act (2005) a person is entitled to make what others may deem to be an unwise decision, provided they are able to retain and weigh up the information and communicate their decision.

Useful Resources:

DSA Mental Capacity webinar

Making every day financial, health and welfare decisions post 16

The Mental Capacity Act: Frequently asked questions

Mental capacity: Decision making and Lasting Power of Attorney

Mental Capacity Act Code of Practice

Social Care – Transition Planning from Age 16/17

If your young person is likely to have care needs after they turn 18, your local authority should undertake a transition assessment. There is no clear timescale for this assessment, but it needs to happen at the point when it is clear what their care needs are likely to be, and it needs to be before they are 18 years old.

The Care Act 2014 states that if a child, young carer or an adult caring for a child (a 'child's carer') is likely to have needs when they, or the child they care for, turns 18, the local authority must assess them if it considers there is 'significant benefit' to the individual in doing so. This is regardless of whether the child or individual currently receives any services. The Act does not say that the child or young person must be a certain age to be able to ask for an assessment, instead the assessment should be when there would be a 'significant benefit' to the individual in doing the assessment. Therefore, there should not be a blanket policy as to when transition assessments take place. In many local areas an Adult Social Care Transition Team will usually start the transition assessment process with you and your young person between the ages of 16 and 17. However, if your young person has more complex needs, it might begin earlier, possibly as early as 14 depending on the level of planning that will be needed.

If, for any reason, the local authority is not be aware of your child/young person you may find that they are not automatically offered an assessment. You will then need to put a request in writing to your local authority for a transition assessment. If the local authority decides not to carry out the assessment at the time of your request, they should give you an indication as to when they believe the assessment should be done in the future and put plans in place to ensure that this happens.

The transition assessment will not result in the provision of services at the time of assessment. It is purely a planning tool for the local authority to ascertain if your young person will need services when they turn 18. It means that the adult team have a record in advance of when they become an adult. In theory, the assessment should enable a smoother transition from children to adult services.

Having carried out a transition assessment, the local authority must give an indication of which needs are likely to be regarded as eligible needs, so that the young person understands the care and support they are likely to receive once children's services cease. Where a young person's needs are not eligible for adult services, they must provide information and advice about how those needs may be met and the provision and support that young people can access in their local area.

The Care Act makes clear that the local authority can combine the transition assessment with any other assessment being carried out for your young person (provided all parties agree). If an external organisation (such as a hospital) is carrying out an assessment around the same time as the local authority's assessment, the local authority can carry out that assessment jointly with the other organisation or on behalf of the other organisation. This allows for sensible and flexible combinations of assessments, which is likely to be in your young person's interest.

When a local authority assesses a child (including a young carer) who is receiving support under legislation relating to children's services, the Care Act requires them to continue providing him or her with that support through the assessment process. This will continue until adult care and support is in place to take over – or until it is clear after the assessment that adult care and support does not need to be provided. This should mean there is no 'cliff-edge' where someone reaching the age of 18 who is already receiving support will suddenly find themselves without the care and support that they need at the point of becoming an adult.

Useful Resources:

Easy Read Guide to The Care Act

Social care and support: social care for children (including transition assessments)

Overview of social care assessments for young adults

My needs assessment booklet (for young people)

Supporters booklet (for parents/carers)

Asking for a needs assessment

Preparing for an assessment

Asking for a carer's assessment

Preparing for a carer's assessment

Getting the care and support plan right (includes information about direct payments/employing a Personal Assistant/carer)

Health – Consent and Decision-making from Age 16

Consent to treatment means a person must give permission before they receive any type of medical treatment, test or examination. People aged 16 or over are entitled to consent to their own health treatment. This can only be overruled in exceptional circumstances. Parents cannot override a competent child's refusal to accept health treatment.

Once children reach the age of 16, they are presumed in law to be competent, and it is therefore presumed that they have sufficient capacity to decide on their own medical treatment unless there's significant evidence to suggest otherwise.

Please read the previous information about mental capacity on page 20 for more detailed information and useful resources.

Consent can be given in the following ways:

- non-verbal – for instance, by holding out your arm for treatment
- verbal – by saying that you give permission have treatment
- written – by signing a consent form giving permission to have treatment.

The United Nations Convention on the Rights of Persons with Disabilities says that people with disabilities have the right to:

'Enjoy legal capacity on an equal basis with others in all aspects of life' and should have access to 'the support they may require in exercising their legal capacity.'

Legally a parent/carer will continue to make decisions for a young person if they are 16 or 17 and both of the following apply:

- they do not have mental capacity for the specific decision
- the parent/carer has what the law calls 'parental responsibility'.

You can only give consent on behalf of your 16 or 17 year old young person if they are legally unable to consent for themselves. Many people who have Down’s syndrome are denied capacity just because they have not had proper support to make decisions for themselves. It is important that accessible information and reasonable adjustments are made to enable young people who have Down’s syndrome to make as many decisions for themselves as possible.

If a young person does not have the capacity to decide about their treatment and they have not appointed a lasting power of attorney (LPA), healthcare professionals treating them can go ahead and give treatment if they believe it's in their best interests. Before they can do this, they must take reasonable steps to discuss the situation with the person's friends or relatives before making a best interest decision. While only one person with parental responsibility needs to be approached, it is good practice for them to involve all those close to the child if possible.

When your young person reaches 16 years old, you can write to your GP, or any health professionals involved with your young person’s healthcare, to remind them of your parental right to be consulted in any best interest decision and ask them to note this on your young person’s file.

Parents/carers cannot give consent for young people aged 18 years or over, even if they cannot consent for themselves. The only exception to this is if you have applied successfully for an Order from the Court of Protection. If your young person is over 18 and lacks capacity and you don’t have an Order from the Court of Protection, the proposed treatment will be discussed with you, but the treating team will make the final decision in the best interests of the young person.

Useful Resources:

NHS Consent to treatment

NHS Learning disabilities

NHS Reasonable adjustment flag

Information about health issues for people who have Down's syndrome

Reasonable adjustments in healthcare

Reasonable adjustments video from NHS

DSA Webinar Decision making from 16 years old

Easy Read: Making Choices

Support with decision making

Listen, Include, Respect

Benefits from Age 16

When your child reaches 16, the benefits that they claim and that you can claim for them as a dependent, may change.

If your child receives Disability Living Allowance (DLA), the DWP will contact you around the time of their 16th birthday, inviting them to apply for Personal Independence Payment (PIP) by a certain date. The letter will also ask whether the young person will need an appointee when they turn 16 and the bank account details for their PIP to be paid into after they turn 16. Being an appointee only gives you the power to manage their benefits. It does not give you the same authorisations as power of attorney or deputyship.

As an appointee you're responsible for making and maintaining any benefit claims. You must:

- sign the benefit claim form;
- tell the benefit office about any changes which affect how much the claimant gets;
- spend the benefit (which is paid directly to you) in the claimant's best interests;
- tell the benefit office if you stop being the appointee, for example the claimant can now manage their own affairs.

The DWP will determine whether an appointee is needed and whether you will be a suitable appointee. If they agree you can be your young person's appointee, they will send a form confirming that you have been formally appointed. You are not an appointee until this happens. Once you're authorised, DWP will monitor the situation to make sure it's still suitable for you and the claimant.

Like DLA, PIP is to help with extra disability related costs. Your young person's needs will be assessed under different rules though. The benefit is awarded on a points-based system, with descriptors and points awarded for various activities. The scores will determine what rates will be paid. There is no day/night distinction as there was with DLA care and the mobility criteria is more generous than DLA.

PIP is made up of two parts, the daily living component and the mobility component.

- The daily living component is paid to someone who needs extra help with personal care. The extra care needs should have been needed for 3 months prior to claiming and be expected to last at least for the next 9 months.

  There are 2 rates, standard and enhanced.

- The mobility component is paid to someone who needs help with getting around. There are 2 rates, standard and enhanced.

You can receive the care component, or the mobility component, or both.

PIP can be spent in any way that benefits your young person. You can claim PIP no matter what your income or savings are. It is not means-tested. An award of PIP will not reduce other benefits you may already receive. It is paid on top of these.

When you apply for PIP, your child's Disability Living Allowance (DLA) payments will continue until a decision is made about their PIP claim. You must complete the form and provide additional evidence by the date stated to ensure that you do not have a gap in benefit payments. If you do not apply by the date in the letter, their DLA payments will stop. It takes an average of 14 weeks to get a PIP decision, but it can take longer.

Carer's Allowance will continue if you are not working or within the earnings limit, and still caring for your child who gets PIP.

Child Benefit, and any Child Tax Credit or Universal Credit that you receive for your child may continue to be paid until they reach 20 if they are still in education. Universal Credit can be paid to someone aged 16 or over no longer in education, but this is rare. If your young person is in full-time education, it can be paid if they are a student without full parental support or they have limited capability for work (after having a work capability assessment). The rules are complicated so please call us for help with this as there are ways to have the Work Capability Assessment carried out.

Telephone Helen on 0333 1212300 or email helen.wild@downs-syndrome.org.uk.

When your child claims benefit in their own right, such as Universal Credit, they will no longer be part of any claim that you may have, such as Child Benefit, Child Tax Credit or any child amount of Universal Credit. Some families will be better off staying with existing benefits until they come to a natural end (usually before age 20).

When your child turns 16, you should seek advice as to whether it's better for you to claim benefit for them in their own right, or not.

If you, or members of your family, are subject to immigration control, please get advice before claiming any benefit. If you claim wrongly, you may put your stay in the UK at risk.

Useful Resources:

Benefits at 16

Benefits at 16 Easy Read

Guidelines to claiming Personal Independence Payment from age 16

How PIP points are awarded (Citizens Advice)

Universal credit

Easy Read: Benefits after 16

Benefits in supported living or residential care

Benefits help for carers

Benefits calculators

A-Z Benefits and Finance

Education – Age 18+

Some young people with Down's syndrome may stay in school until age 19; others may have already been educated in a college setting. In either case this is likely to be a major transition point where your young person has finished an education course and is deciding on their next steps.

Young people with EHC plans may need longer in education or training in order to achieve their outcomes and make an effective transition into adulthood. Young adults who have Special Educational Needs & Disabilities (SEND) can remain in education up until age 25 with an Education, Health and Care Plan (EHCP) in place until that age if their outcomes have not yet been met. However, it is important to note that there is not an absolute right to continue in education until 25 years old. Local authorities will want to see that any additional education course is offering opportunities for progress, rather than a repetition of previous learning.

A local authority cannot just cease an EHCP because your young person has reached 19 years of age.

A local authority may cease a plan for a 19-to 25-year-old if it decides that it is no longer necessary for the EHC plan to be maintained. In deciding that the special educational provision is no longer required, the local authority must have regard to whether the educational or training outcomes specified in the plan have been achieved. Where an EHCP will still be maintained for a young person aged 19 or over, it must continue to be reviewed at least annually. The plan must continue to contain outcomes which should enable the young person to complete their education and training successfully and so move on to the next stage of their lives, including potential employment and independent living. This will happen at different stages for individual young people and not all EHCPs extended beyond age 19 will need to remain in place until age 25.

It is important to think about whether the young person wants or needs to remain in education and what a particular course might lead on to. It is not always in a young person's best interests to be in education setting to 25 years old. Other options available include supported internships, voluntary work or seeking employment, for instance through the DSA's WorkFit programme.

The DSA WorkFit programme brings together employers and job-seekers who have Down's syndrome. It is a tailored and person-centred service dedicated to training employers about the learning profile of people who have Down's syndrome so that they can be supported on their career pathway. The focus is on finding the right employment opportunities for people who have Down's syndrome and ensuring that they have the support they need to be successful in the workplace.

There are a range of employment options that are supported by the DSA WorkFit programme, whose officers provide specialist knowledge and training to support successful and tailored opportunities:

Permanent paid work, with a standard probationary period can work effectively if it is developed to focus on the strengths of the individual. The DSA WorkFit Officer will work with the employer to look at existing job descriptions and business needs to carve out a suitable role. They will also brief and train workplace buddies (a successful part of the DSA WorkFit model that removes the need for job coaches, and then provide ongoing support). Work patterns are negotiated by the DSA WorkFit Officer based on the individual's preferences.

Work experience placements are a useful way to introduce an individual to the world of work and often lead on to an extension to the initial contract, resulting in permanent paid work for many and offering valuable experience and confidence building for those who take part. This format is useful for those with little or no previous experience as they may be unsure of the type of work or industry sector that may suit them. Work patterns are negotiated by the DSA WorkFit Officer based on the individual's preferences.

Inclusive apprenticeships aims to provide equal access and opportunities for all apprentices, including those with disabilities by helping employers create diverse, equitable, and accessible workplaces. Inclusive apprenticeships can consider the individual needs of learners, including learning disabilities and autism. Exemptions are in place for the regular English and Maths minimum requirements. This exemption allows the apprentice to use an Entry Level 3 qualification in English or Maths as an acceptable alternative. There is often a requirement for the individual to work and study for around 35 hours per week.

Supported internships provide a structured, work-based study programme for 16 to 24-year-olds with SEND, who have an EHCP. The core aim of a supported internship study programme is a substantial work placement, facilitated by the support of an expert job coach. Supported interns are enrolled and supported by a learning provider, for example, a school or college, but spend most of their learning time - typically around 70% - in a workplace. There is no legal requirement or expectation that the supported intern will be paid. Supported internships are exempt from the National Minimum Wage regulation and there is often a requirement for the individual to work and study for around 35 hours per week.

Voluntary work for third sector organisations. This format is useful for those with little or no previous experience who do not wish to be paid, to have the most flexibility around work. Also, they may be unsure of the type of work or industry sector that may suit them. Work patterns are negotiated by the DSA WorkFit Officer based on the individual’s preferences.

We suggest that you spend time looking at colleges and other training, employment or care options at least a year before the young person is due to leave their existing school/college.

Be aware that funding can be difficult to obtain to continue in education to 25 years, particularly for specialist residential courses. Given that residential courses have a care element, you may need to involve adult social care as well to secure these placements.

Entitlements to benefits will also change if your young person is no longer living in the family home for some or all the year. It is important to seek advice on what the changes might mean for your family.

Useful Resources:

Further education 16-24 years

Information about benefits in residential college

Down’s Syndrome Association WorkFit

DSA WorkFit Easy Read

Benefits and work

Natspec - specialist colleges

Association of colleges - specialist colleges

NDTi Supported internships

NDTi Supported internships Easy Read

Mencap Easy Read guides to finding work

Adult Social Care – 18yrs+

The core purpose of adult social care and support is to help people to achieve the outcomes that matter to them in their life. Local authorities must promote wellbeing when carrying out any of their care and support functions in respect of a person. This may sometimes be referred to as 'the wellbeing principle' because it is a guiding principle that puts wellbeing at the heart of care and support.

The Care Act 2014 assesses a person's needs for care and support and the outcomes they aim to achieve. These outcomes include:

Personal hygiene

Being able to wash themselves and their clothes.

Nutrition

Being able to access food and drink, and prepare and consume it.

Toileting

Being able to manage their toileting needs.

Clothing

Being appropriately clothed.

Home safety

Being able to use their home safely.

Home environment

Maintaining a habitable home environment.

Relationships

Developing and maintaining family or other personal relationships.

Work, education and volunteering

Accessing and engaging in work, training, education, or volunteering.

Local community

Making use of necessary facilities or services in the local community, including public transport and recreational facilities or services.

The care and support provided under the Care Act 2014 should work to actively promote wellbeing and independence and local authorities should not just wait to respond when people reach a crisis point. Early intervention is key to helping people retain or regain their skills and confidence and prevents need or delays deterioration wherever possible.

Adults who have Down's syndrome and their families need different levels of support to achieve the things they wish to in daily life. Your young person will have a needs assessment to determine their social care needs, and which needs are eligible to be met by public care and support. If they have not already had one as part of the transition process, contact Adult services at your local authority and ask for a needs assessment. Adult social care will consider several factors, such as:

- the person's needs and how they impact on their wellbeing – for instance, a need for help with getting dressed or support to get to work;
- the outcomes that matter to the person – for example, whether they are lonely and want to make new friends;
- the person's other circumstances - for example, whether they live alone or whether someone supports them.

During the assessment, the assessor will want to understand about the everyday tasks your young person struggles with. The aim is to get a full picture of the person and what needs and goals they may have. You can be present as their parent/carer to support them to explain their situation and to take notes if necessary. Alternatively, they could use an independent advocate to support them through the process.

After the assessment, the local authority must determine whether the person is eligible for care and support. As part of the process, the authority must consider other things besides services that can contribute to the desired outcomes, and whether any universal preventative services or other services available locally could help them stay well for longer. If the needs assessment finds that your young person does not qualify for care and support, the local authority should still give you free advice about where they can get help in the local community.

A young person will have eligible needs if they meet all the following criteria:

- they have care and support needs because of a physical or a mental condition;
- because of those needs, they cannot achieve two or more of the outcomes specified;
- as a result, there is a significant impact on their wellbeing.

When determining eligibility, local authorities must consider whether all three conditions are met.

Local authorities must ignore care and support provided by a carer when determining eligibility for an adult.

Where the young person has eligible needs, the authority will produce a care and support plan and discuss this with them. Under the Care Act, there is more flexibility to focus on what the person needs and what they want to achieve, and to design a package of care and support that suits them. 'Meeting needs' allows for different approaches, so that they can get the right level and type of care and support when they need it.

The local authority must provide the adult with a copy of their assessment and their eligibility determination. The care and support plan will set out the type of support needed, how it will be provided (including whether a personal budget and direct payments will be provided) and how much money will be spent on the care provision.

The care and support plan will be reviewed regularly to see what's working and not working, and if it's still the best support for your young person. This usually happens within the first few months of support starting and then once every year.

Adult social care provision is not free. Where a local authority arranges care and support to meet a person's needs, it may charge up to and including the full amount depending on circumstances. The overarching principle is that people should only be required to pay what they can afford. When choosing to charge, a local authority must not charge more than the cost that it incurs in meeting the assessed needs of the person. Whether your young person will have to pay towards their adult social care costs will be determined by their income and savings/assets. To help encourage people to remain in or take up employment, earnings from current employment must be disregarded when working out how much your young person has to pay.

Your young person will need to have a financial assessment that determines how much they need to contribute towards their care. As a general rule, if your young person has less than £23,250 in savings and investments, their care will be paid for partly or in full by the LA.

The Care Act 2014 statutory guidance in England states that the local authority must leave an individual with enough money 'to pay for necessary disability-related expenditure (DRE) to meet needs which are not being met by the local authority'.

Examples of DRE include:

- Healthcare or health related purchases
- Incontinence pads
- PPE
- Equipment for monitoring or communication (including phones/tablets)
- Accessible vehicle costs
- Cleaning/online shopping fees
- Taxis if public transport is not accessible
- Laundry costs
- Subscriptions eg. for apps or personal alarms
- Heating/water/electricity use
- Special clothing or footwear
- Special dietary requirements
- Contribution to rent and bills

Some local authorities use a set amount to cover disability related expenditure, but if you think what your young person spends on disability related costs is higher than that set amount, you should let the local authority know. Once the local authority has assessed income/assets and living costs/DRE, there will be an amount of money remaining from which your young person could be asked to pay charges for their care and support.

If your young person has complex health needs that the local authority cannot meet, the NHS might pay for this care, and they will not have to contribute to the costs. This type of funded care is called NHS continuing healthcare.

Useful Resources:

Asking for a needs assessment

Preparing for a needs assessment

My needs assessment booklet

Assessments: how they should work

Getting the care and support plan right (includes information about direct payments/employing a Personal Assistant/carer)

Disability Related Expenses

Financial assessment (means test) for social care

Social care and support: support options

NHS continuing healthcare

Someone to speak up for you (advocate)

SCIE Quick guide to eligibility outcomes under the Care Act 2014

Adult Health – 18yrs+

Please read this section in conjunction with the section on health from 16 years on page 25.

Reasonable adjustments

People who have Down’s syndrome should expect the same quality of healthcare from the NHS as anyone in the population. If a person who has Down’s syndrome and/or their supporter visits a health professional with their worries or concerns, they should always expect what they have to say taken seriously.

The Equality Act (2010) states all organisations including health and social care, such as hospitals and GP surgeries must take steps to remove the barriers individuals face because of disability.

The NHS must make it as easy for disabled people to use health services as it is for people who are not disabled.

Reasonable adjustments can include:

- a carer being present
- providing plain English or easy read appointment letters
- giving someone a priority appointment if they find it difficult waiting in their GP surgery or hospital
- offering a longer appointment if someone needs more time with a doctor or nurse to make sure they understand the information they are given
- having a quiet space available for people waiting for their appointment

Consent to treatment

Adults are presumed to have sufficient mental capacity to decide on their own medical treatment, unless there is significant evidence to suggest otherwise. Capacity means the ability to use and understand information to decide, and communicate any decision made. A person's capacity to consent can change. For example, they may have the capacity to make some decisions but not others, or their capacity may come and go.

In some cases, people can be considered capable of deciding some aspects of their treatment but not others.

If someone makes a decision about their treatment that other people would consider to be irrational, it does not necessarily mean they have a lack of capacity, as long as they understand the reality of their situation.

Parents/carers do not have an automatic right to make decisions for their adult children who have Down's syndrome.

In certain circumstances it is possible for parents/carers to have formal authority to make decisions on behalf of someone else. Under the law, decision making is split into two categories. These are health and welfare decisions and financial decisions.

For any big or complex decisions where it has been established a person lacks capacity, a formal best interests approach must be taken. A best interests approach must involve anyone who knows the person to whom the decision relates to well. It should therefore involve discussion and consultation with the person's family and/or advocate and any other persons who are involved in the care of the individual (sometimes a doctor, dentist or a social worker depending on the decision being made

If an adult lacks the capacity to give consent, a decision about whether to go ahead with the treatment will need to be made by the healthcare professionals treating them. To decide, the person's best interests must be considered, as discussed above. If it is felt there is nobody suitable to help make decisions about medical treatment, such as family members or friends, an independent mental capacity advocate (IMCA) must be consulted.

In rare and complex circumstances, the Court of Protection may appoint a deputy to make health and welfare decisions on the individual's behalf. A deputy can be a family member, friend, carer or member of staff. A deputy can make decisions on health and welfare, as well as making decisions about money. They can only make decisions when the court tells them they can. This usually happens when lots of decisions need making, not just one.

In the event a person is over 18 and has the capacity to understand what it means to award someone decision making powers regarding their health and welfare, they can decide to use a Health and Welfare Lasting Power of Attorney to give these powers to someone. To grant a Lasting Power of Attorney regarding health and welfare, a person need not have an in depth knowledge about the legal process. It is enough that they understand that they are giving the power to another person to make decisions about their health and welfare in the event they are, in future, unable to make these decisions for themselves.

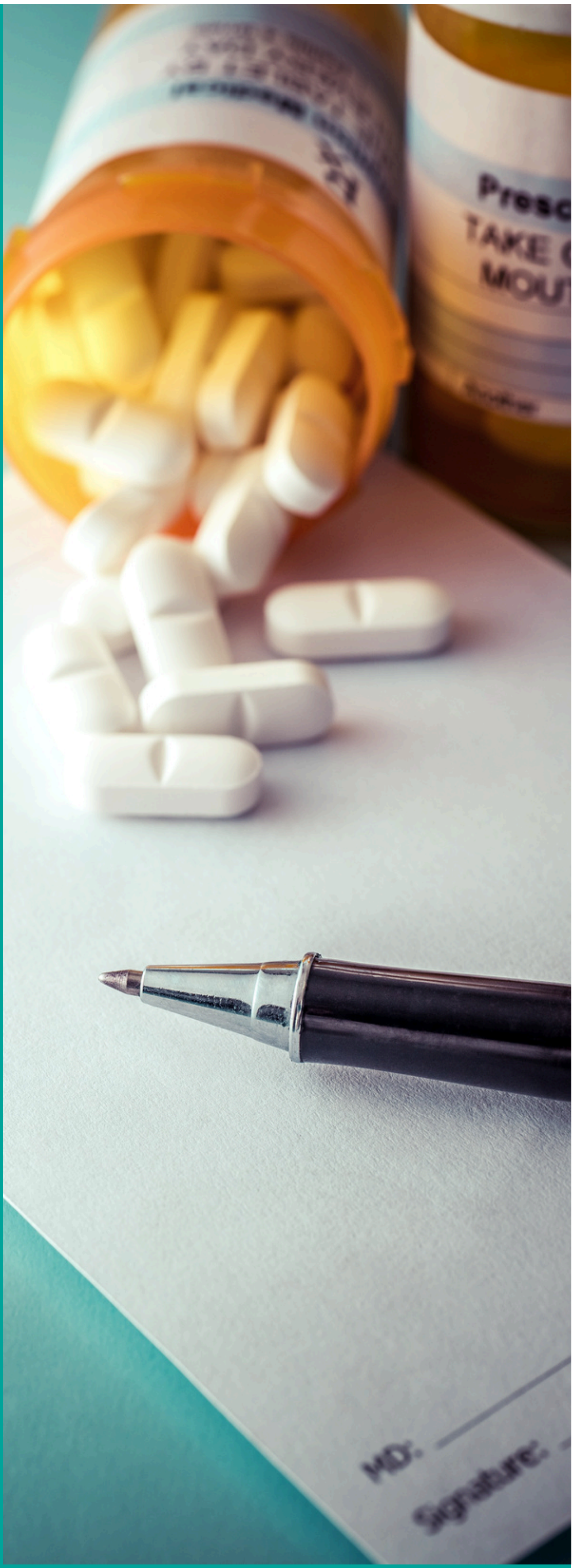
Prescriptions

Prescriptions are free for those under 19 and attending full time education for those living in Northern Ireland, Scotland and Wales. They are also free to other groups, for instance those on certain means tested benefits, pregnant women or with certain medical conditions.

Being in receipt of DLA or PIP does not exempt a person from NHS charges. You can be fined for claiming free medical care if you are not entitled to it. Some of our members have been issued fines because, unbeknown to them, they are no longer exempt from healthcare charges. This is usually because their child has reached 19.

When your son or daughter reaches 19, you can apply for help with NHS costs via the NHS Low Income Scheme. Eligibility depends on weekly income and necessary outgoings, plus savings held. Depending on individual circumstances, your young person can receive "full help" (HC2 certificate) or "partial help" (HC3 certificate). If granted, the HC2 certificate will provide exemption from having to pay NHS charges such as dental or prescription costs.

To apply, you need to call 0300 123 0849 or you can apply online. Your doctor, dentist or optician may also be able to give you a form to complete. Fines can be overturned, and fees paid can be reimbursed once someone has a HC2 certificate after applying on form HC1.



Useful Resources:

Information about health issues for people who have Down’s syndrome

Making financial, health and welfare decisions

NHS Consent to treatment

NHS Learning disabilities

Deputies

Reasonable adjustments in healthcare

Examples of reasonable adjustments

NHS Reasonable adjustments

NHS Reasonable adjustment flag

Reasonable adjustments video from NHS

Rights and care for family member in hospital

NHS Support for going into hospital

DSA Webinar Decision making from 16 years old

Easy Read: Making Choices

Support with decision making

Listen, Include, Respect

NHS Prescriptions

NHS Free prescriptions

Check what help with NHS costs you are entitled to

Managing Money and Benefits – 18yrs+

Please read this in conjunction with previous details about mental capacity, which can be found on page 20.

Managing money

Children do not have direct access or control over money in a bank account until they reach legal age (18 years old). Once they turn 18, a young person becomes legally responsible for managing their own money.

According to the Mental Capacity Act (2005), anyone over 16 must be presumed able to make decisions for themselves, with support if needed, unless it can be shown otherwise. Mental capacity is not a 'blanket decision' – it is situation and time specific. This includes decisions about managing money and bank accounts.

The important thing to remember is that having the mental capacity to understand something is not necessarily understanding all the complex and technical detail – it can be explained in a simple, clear and visual way.

- providing information/letters in easy read formats
- allowing different forms of ID if a person does not, for example, receive bills in their name or have a passport
- allowing to bank in a branch rather than only offering online or telephone banking
- using a chip and signature card if a person has difficulty recalling their PIN number
- providing different types of bank accounts or ways for parents/carers to support the young person with managing their money (eg third party mandate)

Some people are not able to manage their own finances or bank account without support. If this is the case for your son or daughter, there are several things you can do. One option is a Lasting Power of Attorney. This is when your son or daughter gives you the power to look after their finances. To do this, they would need to understand what it means to award someone decision making powers regarding their property and financial affairs. Under a Property and Financial Affairs Lasting Power of Attorney the donor (person giving powers to someone) is able to stipulate exactly which financial decisions they are happy for the attorney (person receiving power to make financial decisions on their behalf) to make. To grant a Lasting Power of Attorney regarding financial affairs, a person need not have an in depth knowledge about the legal process. It is enough that they understand they are giving the power to another person to manage their money and what this might entail.

If your son or daughter lacks the mental capacity to be able to give you power of attorney, you can apply to the Court of Protection for deputyship for property and financial affairs. The Court of Protection handles decisions about people who may or may not lack mental capacity. The Court decides what decisions the deputy can make on the person's behalf. Deputyship is usually not the first option and does have a cost implication, both for applying and processing your application and as an annual subscription fee.

Council Tax

Council Tax is based on two people aged 18 or over living in a dwelling. You normally get a discount if there are fewer than two adults' resident in your household. If there is one adult, discount is 25%. If no one counts as resident in your household, the discount is usually 50%.

Once a young person reaches 18, they will be included in the council tax calculation.

Some people such as students are exempt. People can also be exempt if they are classed as having 'severe mental impairment'. Once your young person is no longer counted as a student, once they have finished being in education, they may be exempt this way. Carers can also be exempt if they care for someone aged 18 or over (who lives with them) for at least 35 hours per week, and that person is not their partner, and they are in receipt of PIP daily living component or DLA middle or highest rate care component.

Have a look on your council website under council tax discounts and disregards/exemptions. In some cases, this can reduce your council tax liability by 25 or 50%.

Useful Resources:

Managing money

Financial decisions for young people who lack capacity

Moneyhelper – helping with every day money

Dosh financial advocacy

Citizens Advice – opening a bank account

Benefits and work

Benefits from Age 16 Easy Read

Work capability assessment

Council tax support

Help with the cost of living

Paying bills – Easy Read

A-Z Benefits and Finance

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