DSUK
Down Syndrome UK

Future Pathways

Part 4: Future Planning



Introduction

Many parents tell us that thinking about "what happens when we are not here" is the hardest part of planning. It can feel overwhelming, and easy to put off.

But a few well-chosen steps, taken early, can make an enormous difference to the person you love and to those who will support them.

In this future planning guide, start with the **Mental Capacity Act** and then follow the four tools:

1. **Appointeeship**: managing benefits
2. **Lasting Power of Attorney (LPA)**: planning ahead with legal authority
3. **Deputyship**: when the Court appoints someone to make decisions
4. **Wills and trusts**: leaving money and property safely



The Mental Capacity Act 2005, Lasting Powers of Attorney and the Court of Protection apply in **England and Wales,** so most of this guide applies in both. **References to benefits and social care charging (from Parts 1 to 3) apply in England only.** Scotland (Adults with Incapacity (Scotland) Act 2000) and Northern Ireland (Mental Capacity Act (Northern Ireland) 2016) have different laws, tools and terminology, and wills, trusts and tax rules also differ. Separate guides for those nations are being produced. If you live in Scotland or Northern Ireland, please don't rely on this guide.

Named examples are made up to show how the tools work. They are not real people.

Please read: this is not financial or legal advice. This guide is general information, shared in good faith by parents and Down Syndrome UK from our own experience and research. Rules and figures change, and every family's situation is different. Always check with the right organisation, and take professional advice, before making decisions.

A common surprise: parents do not have automatic legal authority

When a young person turns **18**, parents **no longer have automatic legal authority** to make decisions for them, even if the young person has a learning disability. This applies to money, healthcare and where they live. Many parents are not told this. It does not mean parents lose their role. It means that, from 18, decisions are made under the **Mental Capacity Act**, and some arrangements need to be put in place formally.

Key terms

Term	Plain English meaning
Mental capacity	The ability to make a particular decision at a particular time.
Best interests	The legal test for making decisions on behalf of someone who lacks capacity for that decision.
Appointee	Someone authorised by the DWP to manage another person's benefits.
Lasting Power of Attorney (LPA)	A legal document in which a person (the donor) appoints someone (an attorney) to make decisions if the donor loses capacity in the future.
Deputy	Someone appointed by the Court of Protection to make decisions for a person who lacks capacity.
Court of Protection	The court that deals with decisions for people who lack capacity.
Office of the Public Guardian (OPG)	The body that registers LPAs and supervises deputies.
Trust	A legal arrangement in which trustees hold money or property for a beneficiary.
Letter of wishes	A non-binding letter that guides trustees and carers about how someone wants to be supported.

Start here: the Mental Capacity Act

Almost everything in this part rests on the **Mental Capacity Act 2005 (MCA)**. Understanding it helps you make sense of every other tool.

The five principles

1. **Assume capacity.** Every adult is presumed to have capacity unless shown otherwise.
2. **Support first.** All practicable steps to help the person make their own decision must be taken before concluding they cannot.
3. **Unwise decisions are allowed.** A person is not lacking capacity just because others think a decision is unwise.
4. **Best interests.** If someone lacks capacity for a decision, decisions made for them must be in their best interests.
5. **Least restrictive option.** Choose the option that least restricts the person's rights and freedom.

Capacity is decision-specific and time-specific

Having Down syndrome does not mean a person lacks capacity. Capacity is assessed for a specific decision, at a specific time. A person may be able to:

- choose what to wear, eat and do each day
- decide who they want to spend time with
- ...but need help with a complex decision, such as a tenancy, a major purchase or medical treatment

Capacity can vary with how information is presented, how they feel, time of day, and who is supporting them.

How capacity is assessed

A person lacks capacity for a decision if they have an impairment or disturbance in the functioning of the mind or brain, and as a result are unable to do one or more of the following:

- understand the information relevant to the decision
- retain it long enough to make the decision
- use or weigh it as part of making the decision
- communicate their decision (by any means)

Supported decision-making

Support makes a big difference. Examples include:

- Easy Read information, pictures, Makaton or other communication aids
- giving time, and choosing the right time and place
- using a trusted person to help explain
- breaking decisions down into smaller parts
- practising or using "talking mats" or role play

Something to consider: a communication and decision-making passport.
Some families write a short document, with their young person, to help professionals support them to understand and decide.

You might consider including:

- **how they communicate:** words, Makaton, pictures, gestures, and phrases that mean something special to them
- **how to explain things:** short sentences, visuals, one thing at a time, checking back, giving time
- **the best time and place:** for example mornings, somewhere quiet, with a trusted person present
- **signs they're anxious or haven't understood:** such as saying "yes" to please, going quiet or changing the subject
- **who they trust** to help them understand
- **which decisions they make themselves**, and where they need more support

Share it with social workers, GPs, solicitors, banks and new support staff.
A speech and language therapist can help you make it as useful as possible.

What "best interests" means

When a person lacks capacity for a specific decision, the decision-maker must consider:

- the person's **past and present wishes, feelings, beliefs and values**
- what the person would have wanted
- views of **family, carers and others** who know them well
- whether the person could regain or develop capacity
- encouraging the person to take part as much as possible

Importantly, "**best interests" is not the same as "what the family wants".** Families are consulted but are not automatically decision-makers. The Care Act also says the council must involve carers and others interested in the person's welfare in assessments (see Part 1).

One family's experience.
Within two weeks of one young person moving into supported living, their parents were told an assessment had been carried out.

The young person had said they didn't want their parents to know about their health needs, or when they were upset or ill. From 16, capacity is presumed for each decision, including what information is shared, even with parents. But where someone lacks capacity for a particular decision, such as sharing information about their health, it should be a **best-interests decision**, with family consulted.

Talk with your young person, and agree with the provider how information will be shared, before the move.



What to expect

- Professionals (doctors, social workers, solicitors, banks) should **assume capacity** and offer support first.
- If capacity is questioned, they should explain what decision is being assessed and why.
- You can **challenge** a capacity assessment, ask what support was offered and request a reassessment.
- Different people may assess in different situations: doctors for treatment, solicitors for legal documents, social workers for care decisions.

Which tool for which situation?

Situation	Often relevant tool	Key point
Person needs help managing benefits only	**Appointeeship (DWP)**	Not general legal authority
Person has capacity (with support) to appoint someone to act for them in future	**Lasting Power of Attorney (LPA)**	Must be made while person has capacity
Person lacks capacity for property or financial decisions, and no LPA exists	**Property and financial affairs deputyship (Court of Protection)**	Court process, with costs and supervision
Day-to-day decisions and health decisions	**MCA best-interests process**	Family, professionals and the person work together
Parents want to leave money or property	**Will and (often) a trust**	Specialist advice essential
Person wants to make a will	**Will, with capacity support**	Capacity is specific to making a will



1. Appointeeship

What does it mean?

An **appointee** is a person authorised by the **Department for Work and Pensions (DWP)** to claim and manage someone's benefits on their behalf. It is for people who cannot manage their own benefits, even with support.

What can an appointee do?

- claim and receive benefits
- spend the money for the person's benefit (rent, bills, food, activities)
- report changes in circumstances to DWP
- keep records

Important: appointeeship is not wider legal authority

- It applies **only to benefits managed by DWP**.
- It **does not** cover HMRC matters such as Child Benefit; council benefits such as Council Tax Reduction or Housing Benefit, where the council has its own appointee process; or Social Security Scotland benefits.
- It **does not** give legal power over bank accounts (banks' policies vary, so ask before payments start), tenancies, savings, property, or health or care decisions.
- It is **not** a court order or LPA.
- It is sometimes granted informally and not reviewed, so check that arrangements are working.

Is it right for us?

Many adults with Down syndrome can manage some or all of their benefits with support. Appointeeship should be used only where it is needed. Always consider whether the person could manage with support, in line with the first two principles of the MCA. Some people have a mixed arrangement, such as managing day-to-day money while a trusted person helps with bills and forms.

What to expect

When: around the 16th birthday, ideally when the PIP invitation letter arrives, so the PIP claim is made with you as appointee.

How: phone the relevant DWP line (the PIP line, or Universal Credit). DWP arranges a visit or interview with you and the young person and completes form BF56. You then get confirmation on form BF57: keep it safe, as banks and others will ask for it.

- DWP will ask about the person's situation and whether the proposed appointee is suitable.
- Appointees should keep records of how money is spent for the person's benefit.
- DWP can review or end an appointeeship.

Something that's easy to miss: an appointee is a **role with legal responsibilities**. It should reflect what the person wants wherever possible, and should not become a way for money to be spent on the family's needs.

2. Lasting Power of Attorney (LPA)

What does it mean?

An LPA is a legal document in which a person (the **donor**) chooses one or more people (**attorneys**) to make decisions for them if they **lose capacity** in future.
In England and Wales there are two types:

- Property and financial affairs LPA: money, bank accounts, bills, property. (This can, if the donor wishes, be used while they still have capacity.)
- Health and welfare LPA: medical treatment, care, where to live. (This can only be used if the donor lacks capacity for the decision.)

An LPA must be registered with the Office of the Public Guardian (OPG) before it can be used.

Key point: the person must be 18 and have capacity to make an LPA

To make an LPA, the donor must **understand** what an LPA is and the effect of giving someone this power. **Many adults with Down syndrome can make an LPA with the right support**, especially with accessible information and time. Others cannot. The test is about **this decision**, not about the diagnosis.

- Ask a solicitor experienced in working with people with learning disabilities.
- The "**certificate provider**" (an independent person) must confirm that the donor understands the LPA and is not being pressured.
- If capacity is uncertain, take advice early. Capacity can be supported and assessed properly.

Why it matters

- It is **quicker, cheaper and less intrusive** than a court deputyship.
- It allows the person to **choose who** will act for them.
- It is a powerful form of **supported decision-making** if done carefully.

What to expect

- The LPA can be made on paper or online, with a solicitor or independently.
- The OPG registration fee is **£92 per LPA** (from 17 November 2025). A person making both types pays for each. Exemptions and reductions may be available depending on circumstances, and rules changed in February 2026, so check current OPG guidance.
- Registration can take **several months**. Plan ahead.
- The donor can choose **replacement attorneys** and can set preferences and instructions.
- It can be **cancelled or amended** while the donor has capacity.

If the person cannot make an LPA

If the person lacks capacity to make an LPA, it cannot be made on their behalf. Options then include:

- relying on the best-interests process for day-to-day and health decisions
- appointeeship for benefits
- a deputyship for property and financial affairs (below)

Parents can, however, make their **own** LPAs, so that someone they trust can manage their affairs if they lose capacity. This is also an important part of planning, because otherwise parents' own finances, which may support their adult child, can be disrupted.

3. Deputyship (Court of Protection)

What does it mean?

A **deputy** is appointed by the **Court of Protection** to make ongoing decisions for a person who lacks capacity, where no LPA is in place.

- A **property and financial affairs deputy** manages money and property. This is the most common.
- A **health and welfare deputy** is rarely appointed. The Court generally prefers that welfare decisions are made through the best-interests process, unless there is a particular reason.

Is it right for us?

Deputyship can be necessary when:

- the person lacks capacity to manage a significant sum, such as an inheritance, compensation or property
- there is no LPA and the person cannot make one
- a bank or other institution requires formal authority
- Many families managing only benefits **do not need** a deputyship. **Appointeeship** may be enough.

You can apply for a **property and financial affairs deputyship from age 16**, so it's in place by 18 if needed.

Costs and responsibilities

Deputyship is a **formal, supervised arrangement**. Typically it involves:

- an **application** to the Court, with application fees and supporting medical evidence
- possibly a **security bond** and ongoing costs
- **annual supervision** by the OPG, including **annual reports** on how money is managed
- strict rules about spending, gifts and investments, and about keeping the person's money separate

Costs of deputyship

Applying to be a deputy costs £432, plus some yearly fees once you are appointed. Many families pay less, or nothing, because of help with fees (see below - fees as at October 2026).

Fee	Amount	When you pay
Court application fee	£432 for each type of deputyship	When you apply
Court hearing fee	£266	Only if the court decides a hearing is needed
Deputy assessment fee	£100, one off	Soon after you are appointed
Annual supervision fee (general)	£320 a year	Each year, due 31 March
Annual supervision fee (minimal)	£35 a year	Each year, for some property and finance deputies managing under £21,000

Fees can change. Check the latest figures at gov.uk/become-deputy/fees before you apply.

Costs that vary

- Capacity assessment. The court needs a form (COP3) completed by a doctor or other qualified professional. There is no set fee. Ask your GP or the professional what they charge before you book.
- Security bond. This is a type of insurance that protects your young person's money. The court will write and tell you if you need one and how much cover. The cost depends on how much money you will manage. You may not need one if the amount is small.
- Solicitor's fees. You do not have to use a solicitor. Many parents apply themselves, online or by post.

Applying for both types of deputyship

If you apply to be both a property and financial affairs deputy and a personal welfare deputy, you pay the application fee twice. Welfare deputyship is rarely granted, so get advice before applying for it.

Who pays?

For property and financial affairs, fees and a bond can be paid from your young person's own money. If you pay at first, you can claim it back once you are appointed.

Help with fees

If your young person gets certain means-tested benefits or has a low income, you may pay much less, or nothing.

Court fees (application and hearing). Apply for help using form COP44A. For a property and financial affairs application, the court looks at your young person's money. For a personal welfare application, it looks at yours.

Supervision and assessment fees. These are charged by the Office of the Public Guardian, which has its own scheme (form OPG120):

Fee	Full fee	Income under £12,000 a year	Certain means-tested benefits
Deputy assessment	£100	£50	£0
General supervision	£320	£160	£0
Minimal supervision	£35	£35 (no reduction)	£0

Apply as early as you can. You may be able to get a refund if you paid a fee you did not need to.

Is there a simpler or cheaper route?

Deputyship is not always needed. Check whether one of these fits first.

Route	Best for	Cost	What it does not cover
DWP appointeeship	Young people whose only income is benefits	Free	Savings, bank accounts beyond benefits, property, Child Trust Funds
One-off court order	A single decision, such as releasing a Child Trust Fund or Junior ISA	£432 application fee (help with fees available), but no yearly supervision fees or reports	Ongoing decisions
Property and financial affairs deputyship	Managing savings, a Child Trust Fund or other money over time	See fees above	Health and welfare decisions

Child Trust Funds.
Most parents who need to go to the Court of Protection to access their young person's Child Trust Fund can ask for the court fee to be waived. Speak to the Child Trust Fund provider first, as they can explain what they need.

What to expect

- The process can take **months.**
- A deputy must act in the person's **best interests** and keep careful records.
- A solicitor can help, though some families apply themselves.
- Compare the costs and effort of deputyship with other options, particularly an **LPA** (if the person has capacity to make one) and **trusts**.

Deprivation of Liberty: the law has changed

In June 2026 the Supreme Court changed the way the law decides whether someone is being "deprived of their liberty". The old test, used since 2014, said this happened when a person was under continuous supervision and control and was not free to leave. That test no longer applies on its own. Instead, each person's situation must be looked at as a whole, and whether the person is content with their arrangements now counts.

This is a big change for young adults who live in supported living, residential care or with family under care arrangements. As at October 2026, courts, councils and the legal profession are still working out how the new approach applies in practice. Clear advice is not yet settled, including on what families can do if they want to challenge care arrangements that may no longer count as a deprivation of liberty.

We will update this guide, and plan a session with a specialist solicitor, once the position is clearer. In the meantime, if you have concerns about your young person's care arrangements, speak to their social worker and get independent legal advice.

4. Wills and trusts

Why it matters

Wills and trusts are where families most often make costly mistakes, usually with the best intentions.

The risk of leaving money directly to the person

If parents leave money, property or other assets directly to an adult child with Down syndrome:

- it can **affect means-tested benefits**: Universal Credit is reduced above £6,000 of savings and stops above £16,000 (2026/27). PIP isn't affected.
- it can **count as capital** in the **financial assessment** for social care, which could mean they have to pay for support (see Part 2: capital limits of £14,250 and £23,250 in 2026/27).
- if the person **lacks capacity** to manage it, a **deputyship** may be needed, adding cost, delay and ongoing supervision.

What a trust can do

A trust lets people you choose (the trustees) look after money or property for your young person and use it for their benefit. For many families the main benefits are:

- **Peace of mind.** Money is managed by people you trust, now and after you have gone.
- **Protecting benefits and care funding**. Money held in the right kind of trust may not count as your young person's own savings when means-tested benefits or care charges are worked out.
- **Tax**. HMRC gives some trusts for disabled people special tax treatment. This can affect Income Tax, Capital Gains Tax and Inheritance Tax. Whether a trust qualifies depends on how it is set up and on your young person's circumstances.

Trusts and their tax rules are complicated, and the right choice is different for every family. This guide cannot give advice. If you are thinking about a trust, speak to a solicitor who specialises in trusts for disabled people, and get specialist tax advice. The Society of Trust and Estate Practitioners (STEP) has a directory of specialists.

Who should be trustees?

- People you trust, who understand the person's needs.
- Consider **more than one**, and **replacements.**
- Consider a **professional trustee** or trust corporation as an option (with fees).
- Consider the **role of siblings**: many parents want to include them without placing too heavy a burden on them.

What about the family home?

Many parents want a child to remain in the family home or to benefit from its value. Options include a trust of the property, or other arrangements. These can be complex and are affected by social care funding rules.
Take specialist advice before making any changes to property ownership.
Part 3 compares buying a home in your young person's name, through a trust, or as their landlord. For shared ownership, see My Safe Home (mysafehome.info).

Something that's easy to miss: transferring money or property to a trust, or to a family member, **to reduce the person's assessed assets** can be treated by the council as "deliberately depriving" the person of capital. The timing and purpose of arrangements matters, and legal advice is essential.

If there is no will

If a parent dies **without a will** (intestate), the law decides who inherits. A child with Down syndrome may inherit **directly**, and without a trust, which creates the problems above. Siblings may also be affected in ways parents did not intend.

Risks of accidental disinheritance

- Leaving everything to one child "to look after" the other has no legal force to **make the child** do so. Leaving assets to a **trust** gives a clear framework.
- Wills should be **reviewed** after significant life events, and in any case every few years.

Wills made by the person themselves

Some adults with Down syndrome want to make their own will. They need **"testamentary capacity"**: broadly, to understand what a will is, what they own and who might expect to benefit. With support and a solicitor experienced in this area, **many can**.

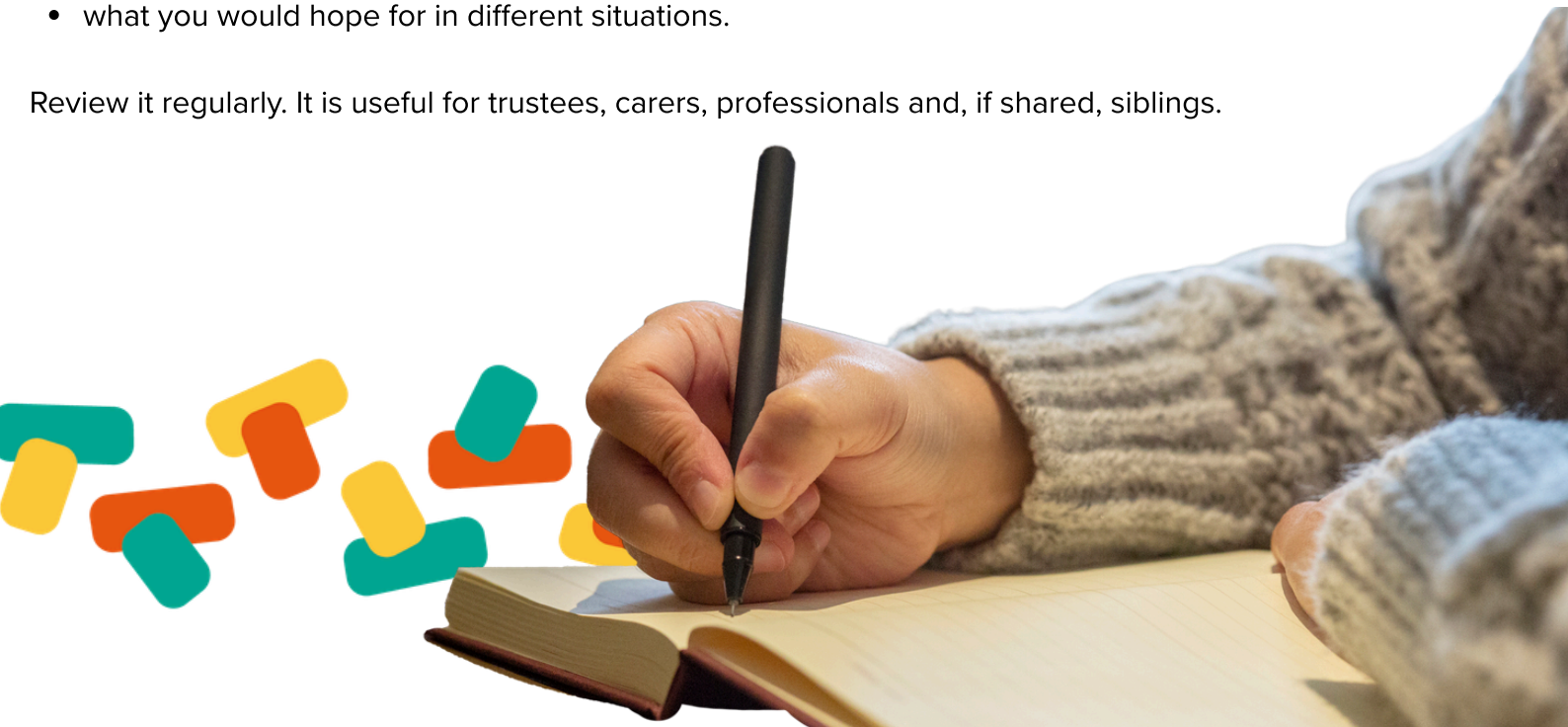
If someone **lacks capacity** to make a will, the **Court of Protection can authorise a statutory will** in some situations. This is a specialist area.

Letter of wishes

A **letter of wishes** is not legally binding but is very valuable. It can set out:

- who the person is: their routines, likes and dislikes, what keeps them happy.
- how money should be used.
- where they want to live and with whom.
- who matters to them.
- what you would hope for in different situations.

Review it regularly. It is useful for trustees, carers, professionals and, if shared, siblings.



An emergency plan

If something happened to you tomorrow, would others know what to do?

An emergency plan can be short, but it should include:

- **who to call**: family, friends, the social worker, the council's contingency and out-of-hours numbers, and the care provider.
- **where key documents are**: LPAs, deputyship order, BF57, benefit letters, Care and Support Plan, wills, bank details.
- **the hospital passport** and a current list of health needs and medication.
- **daily routines**, likes and dislikes, and what helps when they're anxious.
- the **letter of wishes.**
- **who has agreed to step in**, and for how long.

Make sure at least one other person in the family knows where everything is.

Tip: a Circle of Support. Some families bring together a group of relatives, friends and professionals who know their young person well, to share responsibility for decision-making and support in the future. Talk to siblings, relatives and trusted friends early about the role they might play.

What to expect

- A solicitor will ask about assets, family, benefits, the person's needs and capacity.
- Costs vary. Specialist advice is an investment, and getting this wrong can cost far more.
- Take time. This is not a one-meeting decision.

A note on siblings and families

Brothers and sisters often become future trustees, attorneys or main contacts.

It helps to:

- talk early and openly, and listen to what they want, including if they do not wish to take on particular roles.
- make sure roles are shared and realistic.
- ensure the person with Down syndrome has their own voice in who is chosen.



Illustrative examples

These are made-up examples to show how the tools can fit together.

Example 1 (illustrative): Benefits only (appointee)

Rosa, 20, lives with her family and receives benefits. She can say what she wants to spend but cannot manage forms or budgeting. Her mother is her DWP appointee. They keep a simple record and review the arrangement each year.

What helps: a clear weekly budget, Rosa involved in decisions, regular review.

Example 2 (illustrative): A person who can make an LPA

Ben, 28, has a job and lives in supported living. With Easy Read materials and a solicitor who takes time to explain, he makes a property and financial affairs LPA naming his sister, and a health and welfare LPA naming his mother, with his brother as replacement.

What helps: the solicitor assessed Ben's understanding carefully and recorded how he was supported.

Example 3 (illustrative): Parents' will with a trust

Karen and Paul make wills that leave their estate to a discretionary trust for their daughter, Anna, with two trustees (their son and a family friend) and a letter of wishes. They also make their own LPAs.

What helps: they took specialist advice, explained the plan to the siblings, and have reviewed it as Anna's needs have changed.



Checklist: future planning

- [ ] Do we understand that parental authority changes at 18?
- [ ] Have we written down what helps our son or daughter understand and decide?
- [ ] Do we know whether he or she has capacity (with support) to make an LPA, and have we taken advice?
- [ ] Is any appointeeship needed, and is it working?
- [ ] Have we made our own LPAs and wills?
- [ ] Do our wills avoid leaving assets directly to our son or daughter if that would cause problems?
- [ ] Have we considered a trust, and who will be trustees?
- [ ] Have we written a letter of wishes?
- [ ] Have we talked to siblings?
- [ ] Have we taken advice from a specialist solicitor?
- [ ] Have we applied to become appointee around 16, and filed the BF57?
- [ ] If a deputyship is needed, have we applied (possible from 16)?
- [ ] Do we have an emergency plan (see above)?
- [ ] Do we have a date to review everything?

Questions to ask a solicitor

1. What experience do you have of planning for adults with learning disabilities?
2. How will you assess and support my son's or daughter's capacity?
3. Would a trust be better than leaving assets directly, and what type?
4. How will this affect benefits and social care charging?
5. What would happen if there were no LPA or trust?
6. What are all the costs, now and in future?
7. Who should be trustees, and what happens if they cannot act?
8. How often should we review?

Where to find help: a solicitor who is a **STEP** member (Society of Trust and Estate Practitioners, step.org) and specialises in disability trusts and the Court of Protection; the Law Society's **Find a Solicitor**; the **Association of Lifetime Lawyers**; the **Office of the Public Guardian** (GOV.UK); and Down Syndrome UK, including Access Ava (downsyndromeuk.co.uk/parents/social-care) and the DSUK 16+ parents Facebook group.

Myth-busters

"As his parents, we can sign anything for him."

Not after 18. Authority comes from an LPA, deputyship or the best-interests process, depending on the decision.

"An appointee can deal with everything."

An appointee deals with benefits only.

"A direct payment will affect his benefits."

It does not. A direct payment is not a benefit and is not counted as income.

"He has Down syndrome so he can't make a will or an LPA."

Capacity is decision-specific. Many adults with Down syndrome can make these with support. Assess carefully.

"It's simplest to leave everything to him in our will."

It is often the riskiest. It can affect benefits and care funding and may force a deputyship.

"We'll sort it out later."

Some tools **cannot** be put in place after capacity is lost, and others are more expensive and take longer.





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