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Top tips and FAQs for those with a child with Down syndrome

Wills, Trusts, LPAs and financial considerations

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Introduction

This booklet, **‘Top Tips and FAQs for Those with a Child with Down Syndrome - Wills, Trusts, LPAs and Financial Considerations’**, has been created to support families in planning for the future with confidence and clarity.

It provides an overview of key areas such as creating a will, choosing and setting up the right type of trust, understanding lasting powers of attorney (LPAs), the Mental Capacity Act and the best ways to save for your child.

We know these topics can feel overwhelming, so this guide aims to break them down into practical steps and answer the most common questions parents and carers have. Making informed decisions now can offer peace of mind for the years ahead.

Top Tips and FAQs for those with a child with Down syndrome - Wills, Trusts, LPAs and financial considerations

While we use the term 'child', this refers broadly to one's offspring, including individuals of adult age.

1. CREATE A WILL

What is a Will?

A properly drafted Will is a binding legal document which comes into effect when you die and sets out what you want to happen to your property, money, investments etc ("your estate") after your death.

It enables you to give your estate to the people of your choice when you die, it can help protect your estate from having to pay unnecessary inheritance tax and it can do extra things like appoint Guardians for minor children.

For those with a child with Down syndrome or other vulnerable beneficiary, putting an appropriate Will into place is vital. However, you cannot rely on a simple Will that leaves your child with Down syndrome an inheritance absolutely.

Your child with Down syndrome might not have sufficient capacity to manage any inheritance received, they are likely to be vulnerable to financial exploitation or abuse and they are likely to be in receipt of means-tested DWP (Department for Work and Pensions) benefits like Universal Credit and Local Authority provided services and care and support packages etc.

If your child with Down syndrome inherits money from anyone, it will be taken into account in any financial assessment for benefits once they are 18 years old and can detrimentally affect their means-tested benefits and social care and support packages.

A properly drafted specialist Will allows you to leave an inheritance to your child with Down syndrome in a way that protects their means tested benefits and vulnerabilities and protects them from the risk of financial abuse or mismanagement of monies. It will allow them to benefit from the money you have left them improving their quality of life and to pay for things that the State doesn't.

What happens if you don’t have a Will?

You will die Intestate – the Intestacy Rules set out how your assets will be distributed amongst your surviving relatives in a particular order and in particular shares. What you might have wanted is irrelevant.

Children will inherit absolutely under the Intestacy Rules from when they are 18 years old – this will detrimentally impact on any means-tested benefits and care packages of your child with Down syndrome from when they turn 18 years (16 years if in receipt of ESA).

Intestacy myths – your estate will not automatically go to your surviving spouse or civil partner if you don’t have a Will.

It is worth noting that if the estate is worth over £322,000 then although the first £322,000 goes to the spouse/civil partner, the balance will be shared with the children.

The surviving spouse/civil partner might be forced to sell the family home and inheritance tax may become unnecessarily payable.

The Intestacy Rules do not provide for cohabiting couples, stepchildren, friends, or charities that you might have wanted to provide for.

Make the right type of Will

It is advised not to leave an inheritance absolutely to your child with Down syndrome, as it could detrimentally impact their means-tested benefits from when they are 18 years old (16 years old if in receipt of ESA).

For families with a member with Down syndrome, it is not advised to rely on a simple Will. (Simple Wills leave the inheritance to the named beneficiaries absolutely.)

It is advised to use a Will with a particular type of Trust in it or alongside it instead, as this allows you to leave an inheritance for your child with Down syndrome, so there is money ringfenced for them to improve the quality of their life and for them to benefit from, but it is looked after in a way that protects their benefits and services and vulnerabilities.

The Trust must be either a Disabled Person’s Trust or Discretionary Trust.

A Disabled Person’s Trust and Discretionary Trusts are the only Trusts where the money in the Trust is allowed to be disregarded for the purpose of the beneficiary’s means-tested DWP benefits, or any other means tested social care and support packages.

Make sure that family members understand too.

Gifts from Wills from family members cause all the same problems so consider asking them to leave their gifts into a Disabled Persons or Discretionary trust too. They might be able to use the Trust you have created so make sure you discuss this with your Solicitor.

2. USE A TRUST TO PROVIDE FOR YOUR CHILD WITH DOWN SYNDROME

What is a Trust?

Trusts are a way of looking after assets for the benefit of a person or group of people known as the “Beneficiaries”. You name people of your choice, called “Trustees” to look after the assets in the Trust on behalf of the beneficiaries.

Your Will can make a gift into the Trust which is only effective on the date of your death.

There are lots of different types of Trust that can be used for lots of different reasons. There are different ways to set Trusts up and you should always get specialist advice.

When should you use Trusts and what type of Trust should you use?

If you want to benefit someone who suffers from a disability or vulnerability who is unable to manage their own affairs and who might be reliant on means tested benefits or local authority social care and support packages the recommended advice is to use a Trust.
Trusts can be used to pay for anything that your child with Down syndrome wants or needs. They can give money directly to the beneficiary, but that could affect their benefits, so it is safer for the Trustees to agree to pay for things themselves.

Options include either: -

A Discretionary Trust.

- You name the beneficiaries who can benefit from the Trust, your child with Down syndrome will be one of them and you appoint Trustees to make decisions about running and using the Trust. They will be guided by a Letter of Wishes from you explaining the purpose of the Trust and how you want them to act.
- This type of Trust is flexible and future proof. It has the option to be changed to a more tax efficient or different Trust if your beneficiaries’ circumstances and the law/tax changes.
- There may be tax consequences that you will need to discuss in detail with your Solicitor.
- There are pros and cons of using a Discretionary Trust.

A Disabled Person's Trust

- These are Trusts for people who fall within in a statutory definition of disabled. Being in receipt of PIP or DLA at the highest or middle rate for care or highest rate for mobility qualifies the person.
- Only your child with Down syndrome can benefit from the Trust (except for a very small amount each year). You name other beneficiaries who can benefit after the disabled beneficiary has died. You appoint Trustees to make decisions about running and using the Trust and they will be guided by a Letter of Wishes from you explaining the purpose of the Trust and how you want them to act.
- They are supposed to be a tax efficient Trust for a disabled person, but they can be inflexible in their use and can't be changed in the future.
- They need careful thought and detailed discussion as they also have pros and cons. Please do not assume that just because your child is disabled that this is the right trust for you.

Setting up the Trust

You can set up the Trust as part of your Will.

- Leads to a complex Will
- Only the assets that come from your Will pass into the Trust
- Overall, it is probable that solicitors fees will be less to put into place than using a separate Trust

Another option is to set up the Trust separate from your Will.

- If you have pensions, death in service benefits or life insurances, these are not dealt with by your Will so you should look at the option of setting up a separate Trust.
- If you have family members who want to leave something to your child with Down syndrome, it is suggested you set up a separate Trust which they can also use.
- Leaves your Will much simpler and easier to change in the future
- More expensive to get set up

Trustees

Trustees decide how to use the money and property in a Trust.
The person the Trust is for (the beneficiary) will have to ask the Trustees for money or things they need.

It is recommended you choose Trustees who understand the disabled person's best interests and are trustworthy and reliable.

Trustees must communicate regularly and agree all decisions. They could be:

- a relative or friend who knows the disabled person
- a paid professional, which could be a trust corporation

You need between 2 and 4 people to be Trustees.

The Letter of Wishes

This is a side document where you set out why you have created the Trust and how you want the Trustees to benefit your child with Down syndrome. You can explain your child’s needs, likes and dislikes. This document will be valid for a long time, so it is important to consider your future hopes and expectations.

However, you do not have to try and cover every eventuality as the Letter of Wishes can be updated regularly and easily by yourselves. You can also explain what you want to happen to the monies in the Trust if there is anything left after your child with Down syndrome has died.

Although not legally binding, the Trustees do have to consider it and take it into account each time they make decisions about the Trust, and they would have to have good reasons to go against it.

The Letter of Wishes can be updated regularly to keep your trustees up to date with your child’s circumstances.

Other reasons for using other types of Trusts in your Will/Trust

- If you are concerned about protecting your assets from being used to fund your own care home fees in the future.
- If you have children from a previous relationship you might want to protect your estate for them whilst at the same time ensuring that your current partner is also provided for. This may also cover protecting against family of the survivor's future relationships
- If you wish to make sure that your chosen beneficiaries receive your estate and that it’s protected from the risk of the surviving spouse remarrying, or changing their Will, or from the divorce or bankruptcy of your beneficiaries.
- If you wish to benefit an elderly dependent or infirm relative but don’t want anything you leave them to be lost in the payment of their care home fees.
- If you own an interest in a trading business or farm and want to preserve any business property relief or agricultural property relief.

This is not an exhaustive list but a prompt for you to consider and discuss with your Solicitor if any of these or other scenarios apply to you.

3. LASTING POWERS OF ATTORNEY AND DEPUTYSHIP

Lasting Powers of Attorney – for yourself

These are just as important to put in place as a Will. A lasting power of attorney (LPA) is a legal document where you authorise another person or persons (known as your "attorney") to act for you if you have lost capacity and cannot make your own decisions.

They are not just for old people; accidents and illnesses can affect anyone.

Spouses/civil partners are not automatically entitled to look after the money or make decisions about the health of the other if the other has lost their capacity.

There are two types – one that deals with your money and property and one that deals with your health and welfare. You can choose to do one or both types of LPA.

If you don’t have an LPA in place and you lose mental capacity, it will be necessary for someone to make an application to the Court of Protection in order to act on your behalf. This application can be costly and takes at least 4 months and usually longer, for the Court of Protection to process.

Should you consider LPAs for your child with Down syndrome?

It's important to remember that it is not you who puts an LPA into place for your child with Down syndrome. It is the person with Down syndrome who chooses whether or not to put an LPA into place.

Just because your child has Down syndrome, does not mean that they automatically do not have capacity to make an LPA.

Your child with Down syndrome has to be over 18 years old and has to have sufficient capacity to understand what an LPA is, to decide whether to do an LPA, who to name as Attorneys, how to set them up, and they have to be able to weigh up the pros and cons of doing or not doing LPAs.

Their capacity should be established by health care, social care or legal professionals or other independent assessors who are experienced in assessing capacity for LPAs and not just a friend. If the validity of the LPA were ever successfully challenged, the Attorneys could find themselves personally liable for monies spent by them under the invalid LPA.

If your child with Down syndrome has sufficient capacity, it is certainly worth considering helping them to prepare LPAs.

Consider helping them with these easy read guides shared by Mencap Trust Company:-
www.mencaptrust.org.uk/guides-lasting-power-attorney

4. MENTAL CAPACITY ACT 2005

A common misunderstanding is that if a person has a learning disability, their family or caregivers automatically have the right to make decisions for them throughout their lives. However, **this is not the case** under the **Mental Capacity Act**. Once a child reaches the **age of 18, they are considered to have full legal rights**, even if they have a learning disability, therefore for someone to make decisions for another individual (even a close family member), there must be an official legal document like an LPA in place. Without this, a person does not have the automatic legal right to make decisions, even if they are close to the individual, and even then it is not a carte blanche to make all decisions.

However, please note that Lasting Powers of Attorney **only come into effect when it is deemed someone does not have the mental capacity to make their own decisions**. This may be a decision that is made ad infinitum, for example when someone has dementia and they have been assessed as not having the capacity now and in the future. In the case of those with Down syndrome, it may be that in some instances it is deemed that they have capacity to make their own decisions but not in others.

It's important to clarify that while **Lasting Powers of Attorney (LPA)** allow someone to make decisions on behalf of another person, **having an LPA in place does not automatically grant parents the right to make all decisions at all times**. The key principle of the **Mental Capacity Act (MCA)** is that decision-making ability is **time- and decision-specific**, which means that just because someone has an LPA, it doesn't give their attorneys the automatic right to make all decisions on their behalf at all times.

Time and Decision - Specific Decision-Making

1. **Capacity Can Change Over Time:**
   The **Mental Capacity Act (MCA)** recognises that a person's ability to make decisions can change from day to day. This means that even if an individual has an LPA, their capacity to make specific decisions may vary depending on the **time** and **type of decision**. For instance, a person may be able to make a decision about where to go for a day out (decision A) on one day but may not have the capacity to decide about more complex matters, like managing finances or medical treatment (decision B), on another day.

Example:
A person with a learning disability may have the capacity to decide which restaurant to go to on a particular day but may lack capacity to make a decision about medical treatment due to illness or stress. The LPA for health and welfare would only come into effect in this situation if the person is deemed unable to make the decision themselves.

2. Time-Specific Use of LPAs:

LPAs can only be used when the person has lost the capacity to make decisions themselves. If a person has the capacity to make a decision at a given moment, the attorney cannot intervene. The decision-making authority granted by the LPA only comes into play when the person's capacity is questioned or deemed to be lacking for that specific decision. This makes decision-making **time-specific** - the LPA is not continuously in effect unless the person lacks capacity at that particular time.

Example: A person might have the capacity to make a decision about their care on one day but, on another day, may not have the capacity to make that same decision due to health changes (e.g., mental fatigue or illness). On the day they lack capacity, the **health and welfare attorney** can step in and make decisions.

The **Mental Capacity Act (MCA) 2005** ensures that people who may struggle to make certain decisions are still supported in the best way possible, while respecting their autonomy. For a parent of someone with a learning disability, understanding the key principles of the MCA is essential.

1. **Presumption of Capacity:** Everyone is assumed to have the capacity to make decisions unless proven otherwise. This includes individuals with learning disabilities - meaning that they are presumed to be able to make decisions for themselves unless there is evidence to suggest they cannot.

2. **Support to Make Decisions:** If someone is struggling to make a decision, they must be given the help and support they need. This could involve simplifying information, offering time to think, or involving others who can assist. The aim is always to enable the individual to make their own decisions where possible.

3. **Best Interests:** If someone lacks the capacity to make a decision, the decision made on their behalf must always be in their best interests. This includes taking into account their past decisions, feelings, beliefs, and values. The MCA requires decision-makers to consult others who know the individual well, like family members, to ensure the decision is truly in their best interest.

4. **Least Restrictive Option:** Decisions made on behalf of someone who lacks capacity should be as minimally restrictive as possible. The aim is to interfere with their rights and freedoms the least amount necessary to protect them.

5. **Time and Decision-Specific Capacity:** Capacity is not a fixed state—it is time- and decision specific. This means that a person may have the capacity to make one decision but not another, or may have capacity to decide on something today but not tomorrow. For example, someone may have the capacity to decide where they want to go for a day out (decision A) but not to decide on something more complex, like managing their finances (decision B). It's also possible that their capacity to make a decision may change from day to day, depending on factors like their mental state, the complexity of the decision, and how much support they are given.

6. **Advance Decisions and Lasting Powers of Attorney (LPA):** The MCA allows individuals to make decisions in advance about their care or to appoint someone (often a family member) as their attorney, who can make decisions for them if they lose capacity in the future. This help ensure that their wishes are respected, even if they cannot communicate them later on.

For parents, the MCA provides a structured approach to making decisions that balance the person's autonomy with protection. It ensures that, even when a person is unable to make decisions for themselves, the process is respectful of their rights and interests, with a clear emphasis on supporting them in making decisions wherever possible.

Should you apply for a Deputyship Order (DO) over your child with Down syndrome?

If a child does not have the capacity to have LPAs set up… then you might need to apply for a DO. Parents are understandably concerned about what happens after their child is 18 years old and who can make decisions about health or look after their money on their behalf.

However, ask yourself if you actually need a Deputyship Order?

If your child with Down syndrome has bank accounts or investments that need administering, and the bank insists, it might be that you need to apply for a Financial DO. These can be obtained if necessary but do seek advice about what is involved before, during and after the process before you embark on an application.

The Mental Capacity Act 2005 provides for Best Interest Decision Making and often, a Health DO is not necessary. The Court of Protection does not make many Health Deputyship orders.
You should seek specialist advice if you believe that you need a Health DO as they are difficult to obtain, although we do see families successfully obtaining them.

5. CONSIDER IMPLICATIONS OF SAVING FOR YOUR CHILD

As your child with Down syndrome approaches adulthood, it's important that you plan carefully for their financial future. Once they turn 18, any money in their name – such as bank accounts, Child Trust Funds, Junior ISAs, investments, or premium bonds – will be considered when assessing their eligibility for means-tested benefits from the DWP and Local Authority care and support packages.

Means Tested Benefit allowances (as of August 2024)

Once your LD child is over 18 years (16 years for ESA), their income and capital need to be below a certain limit for them to be eligible to claim any means tested benefit.

- **DWP benefits**

You should be aware that if they have less than £6,000 of capital (eg savings), then they should be able to claim the full benefit. If they have between £6,000 and £16,000 then they would get a reduced amount.

Over £16,000 they will not receive any benefits.

- **Local Authority services**

Be aware that if they have less than £14,250 of capital, then the Local Authority should pay the full cost. If they have between £14,250 and £23,250 then the Local Authority will pay a reduced amount and your child with Down syndrome will have to contribute.

It is worth noting that they will not be entitled to financial support for social care, if they have more than £23,250 and will have to pay for all their services.

6. LIFE INSURANCES, DEATH IN SERVICE AND PENSIONS

Life Insurance policies

It is advised to check that the policies are held by you in the most tax-efficient way, and it is recommended you talk to your financial advisor.

One option is to consider writing them into a Trust to avoid falling into your taxable estate and getting held up in the probate process. Your financial advisor or Solicitor can help with this.
By writing them into trust there is the option to substantially reduce or even completely eliminate any inheritance tax liability on your death and / or on the death of your spouse or civil partner.

Death in Service Benefits

By having these paid into a Trust instead of directly to your spouse or civil partner, there is the option to substantially reduce or even completely eliminate any inheritance tax liability on the death of your spouse or civil partner.
Be aware that you would need to set up a separate Trust specifically to take these Death in Service Benefits.

Pensions

Make sure you get up to date advice from your Pension Advisor or a specialist Independent Financial Advisor about your particular pension schemes, as they all differ.

However, generically speaking, many private pensions can often pass to beneficiaries of your choice after your death.

Make sure your Nomination forms are up to date. You will probably have nominated your spouse or civil partner to receive it on your death – but what if they die before or with you?

If the Pension Trustees don't know who should benefit then they might simply pay it to the children – if this includes your child with Down syndrome, it means they will become entitled to a share of the pension pot and that will detrimentally impact their means tested benefits and packages of care and support.

Make sure you have made it clear in your Nomination form where you want it to go if your spouse or civil partner etc has also died. The law on Pensions and Inheritance tax is changing in 2027 so make sure you keep up to date through a financial advisor.

7. FINDING A SOLICITOR

STEP

Look for a fully accredited member of the Society of Trust and Estate Practitioners ("STEP") - **Step.org**

They will have the initials "TEP" after their names.
STEP is the worldwide professional body which promotes high professional standards and education for its members, comprising lawyers, accountants, trustees and other practitioners that help families plan for their futures.

The Association of Lifetime Lawyers

Again, consider using a fully accredited member of ALL - **lifetimelawyers.org.uk**
In addition to expert legal knowledge, members undertake a rigorous external accreditation proving their understanding of the key issues that can affect vulnerable and older people.

Legacy

Please consider leaving a lasting legacy by including Down Syndrome UK in your will, helping us continue our work for future generations. Registered charity number 1184564.

With thanks to Helen Taylor TEP, of Helen Taylor Law, for kindly producing these guidelines. DSUK regularly holds information sharing sessions hosted by Helen at which you can hear directly from her and ask general questions.

helentaylorlaw.co.uk/about-helen-taylor-tep