



Keeping savings safe:

When your disabled brother or sister can't manage a large amount of money, who can?

A brief guide to **wills and trusts** for adult siblings of people with a lifelong learning disability and/or autism

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Sibs is the UK charity for brothers and sisters of disabled children and adults
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What's in this guide about wills and trusts?

This guide is for adult siblings of someone with a lifelong learning disability and/or autism. It briefly outlines common questions we receive from adult siblings about wills and trusts. It is designed as a starting point for information and does not replace independent legal or financial advice.

This guide assumes that your disabled brother or sister is over the age of 18. There are many different decisions involved in managing money. It may be that your brother or sister is able to make some decisions (such as buying a sandwich when they are hungry) but need support with others (such as spending or investing a large amount of money). Your brother or sister's ability to make these decisions is referred to as their mental capacity.

Read our guide "*Decision-making and the law: when your brother or sister can't make a decision, who does?*" before continuing with this guide on finances. You cannot manage someone's finances if they have the capacity to do it for themselves.

Being a sibling can be a complex and challenging experience. You are not alone – visit www.sibs.org.uk to meet other siblings at a support group or become a volunteer support group facilitator yourself.

The information in this guide was accurate at the time of writing – March 2018.

When my parents die, am I legally responsible for managing my brother's finances?

No. You do not have any legal duties to manage your brother's finances. It is your choice whether or not to become involved.

Your brother's day to day finances and arrangements for care can be managed by the local authority or by an Individual Service Fund (ISF). If your parents want to leave money to your brother they can set up a trust, which can be managed by a solicitor.

My dad wants to leave money in his will equally between myself and my sister who has a learning disability. Will my sister's benefits be affected when she inherits a large amount at once?

Your sister's benefits could be affected, yes. Leaving a large amount of money to a person with a learning disability and/or autism can result in means-tested benefits and support packages being cut. The local authority may also insist the money is used to fund your sister's care package, until it runs out.

Depending on your sister's ability to manage her money, she may also find it difficult to adjust to new found wealth or may be vulnerable to financial abuse from others.

Instead, it is advisable for your dad to leave your sister's share of the money in a special trust for your sister. It would be in your family's interests to take specialist advice about this.

My parents want to leave everything in their will to me and my sister, and nothing to my brother who has severe learning disabilities because he doesn't have the ability to manage the money. They said we have to look after his share. Is this OK?

This is not advisable. If all of your parents' money and property is left to you and your sister, in legal terms it belongs to you both only. If you and your sister were to experience a divorce or you were to fall out with each other, then your brother's share of the money is not protected. Whilst this plan may be set out with the best of intentions, circumstances and relationships do change over time.

This also leaves you and your sister with a larger amount of savings than you would otherwise have had. It can also result in more tax being paid, and cause complications with the people that you want to inherit from you under your own will.

In addition, there have been known cases of local authorities contesting the wills of parents who have left their money and property to one son or daughter, passing over the disabled son or daughter. The local authority has attempted to reclaim the money, in order to pay for the disabled person's everyday care needs.

Instead, it is advisable to leave assets such as money and property in a special trust for your brother. It would be in your family's interests to take specialist advice about this.

My dad and his partner don't have a will. What is likely to happen to their money and property when they die?

About 4 out of 10 people do not write a will. This means that their money and belongings may not go to the people they want when they die.

If your dad hasn't written a will the law decides what happens to his money and belongings after he dies. These are called the intestacy rules.

These rules are not always right for modern families, especially for people who:

- Are not married, but live together
- Need to look after disabled relatives
- Have children from more than one relationship
- Don't want their blood relatives to inherit

If your dad is married or in a civil partnership, and dies without a will, his spouse is likely to receive most of his estate. If he is not married or in a civil partnership, or if they both die at the same time, then his estate will be divided equally amongst his children. If any of his children have died, then their share will pass down to their offspring.

'Estate' only covers things that he owns in his sole name. Some assets won't pass under a will (e.g. things in joint names, certain insurance policies, etc).

Inheriting part of an estate may cause difficulties for your brother or sister who has a learning disability and/or autism. It may be difficult for them to manage a large amount of money and their means-tested benefits may be affected. In addition, there may be a delay in them receiving money while the estate is divided which may leave them without funds.

Instead, it is advisable to have a will in place and to leave assets such as money and property in a special trust for your disabled brother or sister. It would be in your family's interests to take specialist advice about this.

What is the difference between a will and a trust?

A will is a legal document that details what you would like to happen to everything you own after you die. An executor of a will is a person who makes sure the wishes in your will are carried out, such as who receives your belongings and how your money is divided.

A trust is a legally binding way of transferring assets such as money, property and belongings into the care of trustees. The trustees must then use the assets in the trust in the way that you have set out, for the benefit of another person e.g. your disabled sister or brother who is known as the beneficiary.

What do my parents need to know about arranging their will and setting up a trust that would benefit my brother who has severe learning disabilities?

The best single piece of advice is to find a solicitor who has experience in acting for parents of a person with learning disabilities and/or autism. It is not advisable for your parents to write their own will, as the process of leaving assets to a person with learning disabilities can be complicated.

A trust can be set up within your parent's will. Their solicitor will be able to advise them on setting up the right kind of trust to benefit your brother. Different types of trust will be right for different people depending on their circumstances.

Trustees can be friends, siblings or organisations such as solicitors. As well as stating how they would like the trust to benefit your brother, your parents can also state how they would like the trust to be spent if there are assets remaining after your brother's death.

The laws around trusts can change – it's a good idea to review wills and trusts regularly to ensure they still meet your brother's needs and that the assets would be protected.

My parents want to leave their house to my sister who has Down syndrome, so that she can continue to live in it when they are no longer around. Is it possible to do this and how will my sister manage it?

Yes, a house can be left in a trust for your sister so that she could continue to live in it. If a special trust is used the house will not be considered as owned by your sister and therefore will not be included as part of her assets if she is assessed for means-tested benefits or social care funding.

It is important for your parents to consider:

- How would your sister manage the upkeep of the house?
- Are there sufficient funds in the trust to pay for repairs and maintenance?

- What would your parents like to happen to the house if it becomes unsuitable for your sister's needs?

Different types of trust will be beneficial for different people depending on their circumstances. Find a solicitor who has experience in acting for parents of a person with learning disabilities and/or autism, and can advise on the best type of trust to set up for your sister.

What type of trust fund should we set up for my disabled sister?

This is a really good question to ask. It is not enough to just set up a trust fund – it needs to be the right kind of trust fund for your sister, otherwise it may not work in the way that you want it to.

There is no 'one size fits all' trust fund that is appropriate. You need to seek specialist advice from a solicitor that has experience of acting for a relative of a person with learning disabilities and/or autism, and can advise on the best type of trust to set up for your sister.

There isn't a single accreditation or membership that will guarantee that a solicitor understands this area. Membership of STEP (a professional association for practitioners who specialise in family inheritance) and Solicitors for the Elderly are useful indicators that the solicitor is likely to be aware of the issues, but it's not a cast-iron guarantee. Lots of solicitors are members of one entity, but fewer will be members of both. A solicitor needs a clear picture of how benefits and care funding works and the interaction with trust law.

SIBLING EXPERIENCE: We lost the family home

My three brothers and I grew up in a large house that my parents had built. We were hoping to keep it in the family, but unfortunately it didn't turn out that way.

When Dad died, he left his money and his share of the house to Mum, who was still living there with my brother Michael. Michael has autism, learning disabilities and epilepsy, and Mum was his main carer.

When Mum died, she left the house in her will to Michael hoping he could keep living there and her remaining money was divided between myself and my other brothers.

Unfortunately, Michael couldn't keep living there. Owning a house meant he was no longer eligible for means tested benefits. He no longer had Mum to care for him and he wasn't eligible to receive funding from the council to have carers. The house had to be sold and Michael was moved quickly into a care home that he didn't like and had little choice over – there wasn't time to find anything else.

Since then, the money from the sale of the house has been paying for his care home fees. Only when that runs down, will he be eligible for the council to fund some of his care.

We're still trying to find Michael a better place to live and care that's more suitable for him. The whole thing has been a nightmare. Not only have we lost Mum and we're all still grieving – we've lost our family home. Michael has lost his entire way of life. It has been devastating.

SIBLING EXPERIENCE: Divorce cost the whole family

My mother and stepfather gave my sister Sophie and me a large sum of money well before they died. It was our inheritance and they said we had to split it four ways – a portion each for ourselves, and a portion each for our twin sisters, Harriet and Jayne.

Harriet and Jayne have profound and multiple learning disabilities, rare undiagnosed genetic conditions and complex health needs. Sophie and I have always been close and wanted to look out for our sisters. We talked with our parents about the future, and agreed that the money they had left for Harriet and Jayne would be spent on giving them a better quality of life – extra sensory equipment when they needed it and a short holiday each year. They need two carers each when they go out so the cost of this can add up quickly.

We have always been a close family and I had no concerns about our plan. But five years after our parents' death, Sophie got divorced. The money we had been using to fund Harriet and Jayne's needs was in Sophie's name, and she lost it all in the divorce. My parents worked so hard to make sure that Harriet and Jayne would have a better future – their careful planning was lost in a very short space of time.

Sophie and I were gutted. We wished that we had done something to protect the money. We just didn't think we needed to – but I guess there are always things that happen in life that you cannot predict.

Further reading

"Decision-making and the law: when your brother or sister can't make a decision, who does?"

<https://www.sibs.org.uk/guides-adult-siblings-people-lifelong-learning-disability-autism>

Who can inherit if there is no will? The rules of intestacy

<https://www.citizensadvice.org.uk/family/death-and-wills/who-can-inherit-if-there-is-no-will-the-rules-of-intestacy/>

The Law Society – find a solicitor (Wales and England)

<http://solicitors.lawsociety.org.uk/>

The Law Society – find a solicitor (Scotland)

<https://www.lawscot.org.uk/find-a-solicitor/>

The Law Society – find a solicitor (Northern Ireland)

<https://www.lawsoc-ni.org/solicitors>

Addressing the issue of wills and trusts naturally leads to addressing the issue of death. Dying Matters aims to help people talk more openly about death, dying and bereavement and to make plans for end of life.

www.dyingmatters.org

Next steps in supporting yourself and your disabled brother or sister

What two actions will you take this month as a result of reading this guide?

1.
2.

Further support

Being a sibling can be a complex and challenging experience. You are not alone – visit www.sibs.org.uk for more information, to talk to someone about sibling issues, or to meet other adult siblings at a support group.

About Sibs

Sibs is the only UK charity representing the needs of siblings of disabled people. There are over half a million young siblings and at least 1.7 million adult siblings in the UK, who have grown up with a disabled brother or sister. Sibs aims to enhance the lives of siblings by providing them with information and support, and by influencing service provision throughout the UK.

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Sibs relies on donations and grants to support siblings – please consider making a donation through our website.