

A letter of wishes is not legally binding to your trustees, but it will give them guidance about how to carry out your wishes.

If you choose to set up a trust you will need to consult a solicitor and you should ensure it is one with experience of setting up trusts for people with a learning disability.

Inheritance Tax is a tax that is charged at 40% on the value of your estate above £325,000 (this sum is subject to change) and is payable on your death by your executors.

If you leave 10% of the value of your estate to a charity such as PWSA UK the inheritance tax on your estate will fall to 36%.

Legacies are a valuable source of income to all charities and the Prader-Willi Syndrome Association UK is extremely grateful for any legacies, however small. You can leave a set amount or a percentage of your estate, but whatever you leave is vital to the future of PWSA UK and our work.

Your legacy will help us to provide a brighter future for people with PWS by continuing our work to support families who are still coping with the challenges brought by PWS, and to fund research into finding ways to change the future.

If you would like to leave a legacy to the PWSA UK, please tell your solicitor and give him our full name - **Prader-Willi Syndrome Association UK**, and quote our **Registered Charity Number 1155846**.

Please let us know if you include PWSA UK in your will so that we can thank you properly and keep you informed about our work.

Prader-Willi Syndrome Association UK
Registered Charity No 1155846

Preparing for the future

Making a Will and Setting Up a Trust

Whatever your age

it is a good idea to consider who you would like to benefit from your possessions when you are no longer here. This becomes more important once you have children, and particularly so if you have a child with special needs.

You may have relatives willing to care for your son or daughter when you are no longer able to, or their care may transfer to social services. In either case, a will allows you to direct what happens to your money, property and possessions after your death.

If you have a child or adult with a learning disability, writing a will and setting up a trust will make sure that they will get the financial support and protection that they need when you are no longer here.

If you die without a will, the **Administration of Estates Act** dictates how your money, property and possessions are shared out.

You will need to consider:

- What you own – all your money, property and possessions and how much they are worth – this is your **estate**
- Who you would like to benefit from your will – the **beneficiaries**. This could be family, friends and charities. You can leave specific gifts or percentages of your estate
- Who you would like to officially appoint to make sure your wishes are carried out - the **executor**
- If you have children under the age of 18, who you would like to be their **guardian**
- If you have a family member with a learning disability, should you set up a **trust**? This means that someone else would look after the money for them and you would need to decide who should manage the trust—**the trustees**

Leaving money to someone with a learning disability can present particular issues:

- Depending on how much you leave, monies left directly to someone with a learning disability may affect any benefits they are receiving or may receive in the future, and could be used by social services to pay for their care
- You may consider relying on your other children to carry out your wishes, but this may not always be possible. For example, monies left to a son or daughter so that they can look after the person with a learning disability, could be included into a divorce settlement or unintentionally lost through bankruptcy

Setting up a trust enables you to leave money to provide for a family member with a learning disability without them having the responsibility of looking after it in their lifetime. It is a binding arrangement where money or property is left 'upon trust' to another person or persons - **the trustees**.

The trustees look after and use the trust fund for the benefit of the person with a learning disability. This is usually set out in a trust deed that you make before you die, or in your will, and the trust will start on your death.

A trust offers more protection, as the trustees have control over the trust fund, not the person with a learning disability.

If an adult with a learning disability is, or may become, entitled to means-tested state funding, they can be a beneficiary of a **discretionary or a disabled person's** trust without it being included when they are assessed. This is not true for all trusts – so it is very important that you discuss with a solicitor the type of trust you want and how it might affect rights to state funding.

Monies put into a trust for a person with a learning disability, can be available for them in their lifetime when they need it, for example for holidays, equipment or healthcare. You can also direct where the money should go to on their death, for example to your other children or family members, or to a charity such as the Prader-Willi Syndrome Association UK.

Many people who set up a trust leave the trustees a 'Letter of Wishes'.

This should set out:

- Your reasons for setting up the trust
- Guidance about how you want the trust fund to be used to help and protect your child with a learning disability
- How you would like the remaining monies in the trust fund distributed after your child's death—whether to other family members or your favourite charity