

Wills for people with Down syndrome

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One of the primary considerations of wills for people with Down syndrome is to consider whether they have testamentary capacity, which means the ability to make a will. At law, the test for testamentary capacity has four parts:

- 1 Understanding the nature and purpose of a will
- 2 Understanding, or being able to understand, the extent of their assets
- 3 Being able to use reason to decide who to include in their will
- 4 Not suffer from any medical conditions which overcome their ability to make their own decisions.

Just because somebody has Down syndrome does not mean that they do not have capacity to prepare a will.

A lawyer is the best person to help assess whether someone has testamentary capacity.

Most lawyers will recognise that the presence of a support person can be very comforting and helpful. Some lawyers might ask to see the will-maker alone.



The purpose of this is to ensure that nobody is unduly influencing the will-maker. If this causes distress, you can have a conversation with the lawyer about whether some other arrangement can be made – for example, a support person might be present for part of the meeting only.

Making a will is a very personal matter. No one can make a will on behalf of somebody else. Similarly, no one can bear undue influence on a will-maker to prepare a will in a particular way – a will prepared under undue influence is not a valid will.

It can be helpful to prepare a will-maker for their first appointment with a lawyer by asking them to think about who is important to them in their lives, who has contact with them and provides them with love and support on a permanent and non-commercial basis, and what causes are important to them. It's important that the will-maker can express these things to the lawyer in their own words.

A lawyer might ask a doctor to provide an opinion on whether the person has testamentary capacity. This opinion can be kept with the will. The purpose is not to



help the lawyer, but rather, to help the executor of the will prove that the will-maker had capacity at the time of making their will.

Some lawyers will charge a flat, fixed fee for preparing straightforward wills. Others charge by the hour. It's important to clarify how your lawyer will charge before you start the process. It's also important to ensure that your lawyer makes you feel comfortable and not rushed or confused, that they are using appropriate language, and that they take the time to explain what they are doing and why.

Wills only deal with assets owned by the will-maker in their sole name. Wills don't deal with assets which are in joint names, nor do they deal with assets in trusts of which the will-writer is a beneficiary. For example, if a person has assets held for them in a Special Disability Trust, those assets are usually not part of that person's estate when they die (so long as the Special Disability Trust is set up correctly).

A Special Disability Trust is a way of leaving money to a person who will require help to manage that money. The parents of a person with Down syndrome might put a Special Disability Trust into their own will.

A Special Disability Trust is useful because money in a Special Disability Trust does not count towards a person's right to the Disability Support Pension. It is also useful because the Trustee will manage that money for the Beneficiary, and it will not be in the Beneficiary's bank account. This stops people from taking advantage of the Beneficiary.

Money in the Special Disability Trust is the Beneficiary's money – but the Trustee looks after it for the Beneficiary and gives it to the Beneficiary when they need it or pays it to people who are providing services to the Beneficiary.

A Special Disability Trust can be created in a will, but can also be created at any time, not just in a will. They can be very useful.

If someone does not have capacity to write a will, then the law sets out what happens to their assets. The process is called intestacy. Each state has slightly different intestacy laws. For some people with relatively small estates, or who might not have testamentary capacity, the intestacy laws might be fine.