



## Wills and Trusts

### Protecting your family's future

#### General

Making provision in your Will for a son or daughter with a learning disability requires careful thought and expert advice, because a standard Will is not appropriate. The cost of residential care is expensive, as recent damages awards have illustrated. As much as £4 million has been awarded in some negligence cases when the victim is going to need residential and nursing accommodation for the rest of their life.

Of course, not everybody suffering from a learning disability will be severely affected, and the problem in giving advice on the subject of Wills and Trusts is the enormous variety of situations. These include:

- Living in and cared for by family or a friend at home.
- Living in own home with support (supported living).
- Living on their own, completely, without support.
- Living in a supervised house shared with others or a hostel.
- Living in a Local Authority Residential Care Home.
- Living in a private or charity run Residential Care Home
- Living in a full time Nursing Home or in Hospital.

Apart from the present circumstances that have to be considered, you have to consider possible changes that may take place in the future. Most significantly is the possibility that on a parent's death their offspring might have to move to a different type of accommodation and/or need more help and support.

#### Welfare Benefits

People with learning disabilities and their carers are entitled to a wide range of State Benefits. These fall into a number of different categories.

There are benefits where you have to have paid National Insurance contributions (such as the Contribution based Job Seeker's Allowance,

Incapacity Benefit and Retirement pension). There are some benefits that are means tested, and some that are not.

#### *Non-Means Tested Benefits:*

- Child Benefit.
- Disability Living Allowance. (A 'repackage' of Mobility and Attendance Allowance). This is payable at three different levels.
- Attendance Allowance for the over sixty fives.
- Incapacity Benefit (formerly Sickness Benefit and Invalidity Benefit).
- Severe Disablement Allowance (abolished for new claimants after 6th April 2001).
- Invalid Care Allowance - payable to the Carer.

#### *Means Tested Benefits:*

- Council Tax Benefit.
- Disabled Persons Tax Credit.
- Working Families Tax Credit.
- Income Support.
- Residential Care paid for by the Local Authority.
- Housing Benefit.
- Social Fund.
- Income-based Job-Seeker's Allowance.

#### *Means Tests*

**On Capital.** There are now a wide variety of different capital limits depending on the type of Benefit or support. If you exceed the maximum capital level for the particular benefit then you cannot claim at all. The lowest maximum figure is £8000 for Income Support for under sixties and the highest is £19000 for Local Authority help towards residential care costs. Below these figures there are lower figures where you can still claim the benefit but capital over a certain level is taken into account. For example if a person is under 60 and has capital of over £3000 then for every £250 over this figure there is a loss of £1 per week up to the cut off of £8000. This is the equivalent of 26% interest!

**On Income.** A small amount from a minimum of £5 to a maximum of £25 can be disregarded. Anything over this sum results in a pound for pound loss of Benefit.

When you make your Will you must be sure that it does not result in a loss of means tested Benefits or no real benefit will be gained by the beneficiary.

The types of Benefit available to people with learning disabilities have changed over the years and so have means tests. Any provision that is made in a Will should be flexible to allow for future change.

## Essential Information

Before advising about your Will it is important to check on all Welfare Benefits.

There should be a discussion about the future care of the person with a learning disability. It is especially important to consider where the person will be living after your death and how this will be paid for.

The finances of the person with a learning disability will need to be considered, including the amount of money that is likely to be available for them when you die. You should also think about money that may come from other sources, such as your parents and others.

## The Options

### **1. Leave everything, outright, to the person with a learning disability (or a share, if there are brothers and sisters)**

This will only work if:

There will be no loss of Means Tested Benefits.

There isn't much chance of Means Tested Benefits being needed in the future.

There is little chance of Residential or Nursing Accommodation being needed.

Where the person is able to manage his or her money without help.

### **2. Leave everything to the other children and cut out the learning disabled person.**

You might want to do this thinking that your family and friends will always help if needed. This is a very dangerous option. Anything could happen to your friends and family. Their death, divorce, bankruptcy or even dishonesty could spoil your plans!

More importantly, your Will could be contested under the Inheritance (Provision for Family and Dependents Act) 1975. This challenge could come from the Local Authority or other interested parties and be taken up by the Official Solicitor who represents people with disabilities.

A 'Secret Trust' under which monies are paid to a third party and earmarked for the benefit of a person with a learning disability could involve a Benefit

claimant committing a fraud and being liable to prosecution.

### **3. Set up a Trust solely for the learning disabled person**

This involves leaving either all your money or a share of it to be held by trusted persons called Trustees to hold the money for the learning disabled person. They then pay and use the income and the capital itself for their benefit. The disadvantage of such a Trust is that the income would belong to the learning disabled person and this could result in a loss of means tested Benefits. Also if capital is paid over, under a power to release, this could also result in a similar loss in Benefits. Creating a "Protective Trust" (i.e. one where the release of capital is prohibited) might get round the capital limit problem but there still is the problem with income.

#### **3.1. Charity Schemes**

A number of charities and in particular The Royal Mencap Society have set up schemes to try and help. They have also tried to consider the practical day to day problems of seeing how the person with a learning disability is coping in his or her situation. One aim is to meet needs that are not met through other sources.

Mencap operates many residential care schemes previously referred to as Homes Foundation Schemes. It often provides the care in a home owned by a Housing Association as well as through its own residential care schemes. It provides supported living schemes through its subsidiary charity Golden Lane Housing Ltd.

**Mencap Trust Company Ltd.** This company is a subsidiary of Mencap and it acts as trustee of individual trust funds where there is no suitable relative or professional person able and willing to act. The company cannot act as executor and will only act in trusts set up in its standard form. The Trust is set up as a Discretionary Trust (See below)

The Trust is set up during parents' lives with an initial sum of £5 placed in it. A further sum or a share of your Estate is then left by Will. An information pack which includes the standard form of Trust and form of Bequest is available from The Wills & Trusts Assistant at Mencap on 020 7696 6925 or at [www.mencap.org.uk/willsandtrusts](http://www.mencap.org.uk/willsandtrusts) or by writing to The Wills & Trusts Team, Mencap, 123 Golden Lane London EC1Y 0RT. This type of Trust can be very useful in cases where there are no suitable people to act as Trustees. It considerably simplifies the drawing of the Will, as all that is necessary is to leave either a

set sum or a part of your Estate to the Trust that you have set up.

### **3.2. Discretionary Trust**

A **Discretionary Trust** is where the person making the Will leaves either all of their money or a proportion if there are other children, to Trustees to look after in a Trust fund. The Trustees are given the discretion to pay out income or if necessary lump sums to a range of family members and possibly charities of your choice. The family member with learning disabilities is selected as one of the family members whose needs can be considered in priority. The big advantage of this type of Trust is that for means test purposes the Trust fund and its income are not taken into account (Reg. 51 Income Support (General Regs) 1987). If money is actually paid to the person with learning disability this will be taken into account. Income and capital thresholds will need to be watched carefully.

More usefully the Trustees can apply the income and lumps sums to pay for things directly and Trustees should be given a wide discretion to pay for things not covered by Income Support. These “extras” could be things like holidays, additional items of furniture or equipment, private health care, life insurance and a whole host of other things.

The disadvantages are that some parents find it off-putting that the person with a learning disability is only one of a range of possible beneficiaries. This problem can be overcome by a letter being written to the Trustees setting out the reason for the Trust being set up in this way and giving general guidance on how you would like the Trustees to exercise their discretion's. Care needs to be taken with wording of the letter. There will be some expense in managing the trust and keeping accounts. The tax situation is not particularly helpful but even so a Discretionary Trust has many advantages.

### **3.3. The Combined Package**

Often none of the above options provide the complete solution. Charity schemes in themselves may be all very well but most parents want to do something independently, even if they like the idea of a charity scheme. For many the preferred solution is a tailor-made combination of the possible options.

Perhaps a small lump sum outright: a gift to others: some provision through a charity and the rest in your own personal Family Trust Fund set up as a Discretionary Trust. This may be the best way forward. You will need to give this careful thought and discuss it with your Solicitor.

## **Preparing the Will Itself**

This should be professionally prepared and under no circumstances should any attempt be made to draw the Will yourself. Care should also be exercised in making sure that the solicitor instructed really understands the problems of preparing a Will involving a person who has a learning disability or is prepared to take the time and make the effort to do so. If not, you should find someone else. This is not easy. Local and National Mencap Offices sometimes have lists. Ask around amongst other parents. Use your contacts.

## **Trustees**

If you are creating a Trust you will need at least two Trustees. These are the people who carry out your wishes as expressed in your Will. They will collectively need to maintain close contact with the person with a learning disability and be aware of his or her special needs. They must have the ability to administer a Trust Fund. An ideal combination is often concerned younger members of the family and a professional person. You will need someone with both knowledge of administering a Trust and its inter-relation with Welfare Benefits.

If you decide to set up a trust using Mencap's National Trustees for the Mentally Handicapped Ltd scheme referred to above you will still need executors. Their duties will be to deal with such things as the funeral and realising all your property. They would then hand over the money for your Trust Fund to NTMH Ltd to organise from then on.

## **The Cost**

If you are in receipt of Income Support and some of the other means tested benefits then it may be possible to receive some help under the Legal Help scheme. Ask beforehand if the solicitor of your choice can do this.

If you are not entitled to free Legal Help then the cost will be more than you would pay for a simple Will, as the factors above must be carefully considered and the Will drafted to meet all of those contingencies. The Solicitor of your choice should either give you a fixed fee quotation or let you know the hourly rate he will charge. It is vital though, that you get it right, for your peace of mind and your family's future security.

## **Guardians**

Where the person with a learning disability is under 18 it is desirable to appoint a guardian, i.e. someone who will be legally responsible for him or her. Care must be taken on the initial appointment, which must

be kept under review. Parents or in-laws can often be appropriate during the early years but as time passes may become less able to cope and a switch to a brother or sister might be appropriate. For a person over 18 it is not possible to legally appoint a Guardian but there is no harm in appointing someone as a guardian "in so far as the law allows". Hopefully a change in the law is on the way as The Law Commission is reviewing this.

## Other Problems

Relations and especially grandparents should be advised of the problems and pitfalls in relation to their own Wills. They can cause problems by leaving money to a family member with learning disability. Similarly, there can be problems if you have a Life or Pension Policy, or you are a member of an Employment Pension and Life Insurance Scheme that carries with it a Death in Service Benefit. In this situation the Trustees should be directed that the proceeds of any Employment Related Scheme (which would ordinarily pass outright to your incapacitated beneficiary) are, on your death, to go into the Trust Fund set up under your Will.

If parents or others want to make provision during their lives or on their death before your Will Trust comes into operation you will have to set up a trust in your lifetime. You can do this as a Discretionary Trust if this is your preference. Your Will is then simplified, as you then just need to direct that further money be added to the lifetime Trust Fund.

The law as stated in this Fact-sheet is as of September 2002. It is essential for parties and their advisors to bear in mind changes that take place when further advice may be needed. (For example any move from home to Local Authority accommodation and vice versa, or any substantial change in the family wealth such as an inheritance)

These notes are for general guidance only and the TSA does not recommend any of the above options for a specific member's family and cannot accept

liability. Every situation is unique and parents should take their own independent professional advice before making any decision.

## Leaving money to benefit others with TS.

When you are arranging your Will your first priority will be for your own family, especially for any member with a learning disability. Having done this, at the same time it is possible to help others affected by Tuberous Sclerosis.

By remembering the TSA in your Will you can help the TSA continue it's work:-

- Pioneering research to develop more effective treatments of the condition.
- Supporting families helping them through its network of Support Workers and Clinics.
- Giving financial help to families in need through its Benevolent Fund.
- Bringing those affected by TS together at organised events.
- Helping sufferers within all ranges of the disability.
- Working to build effective mutual support groups.
- Just being there on the end of a 'phone or on-line

A legacy or bequest when you make your Will can help continue this work into the future. All you will need to mention is the TSA's Registered Office of Toad Hall, White Rose Lane, Woking, Surrey GU22 7LB and the Charity Registration Number 1039549.

**Finally** Thank You for reading this brochure and taking the time to plan for the security of those with Tuberous Sclerosis who will be living after you are gone. The knowledge that you have planned for the future should help you to live a long and contented life!

**Graham Harker**  
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Further information on TS and the work of the TSA can be obtained from: Diane Sanson,  
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**Tuberous Sclerosis Association**



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