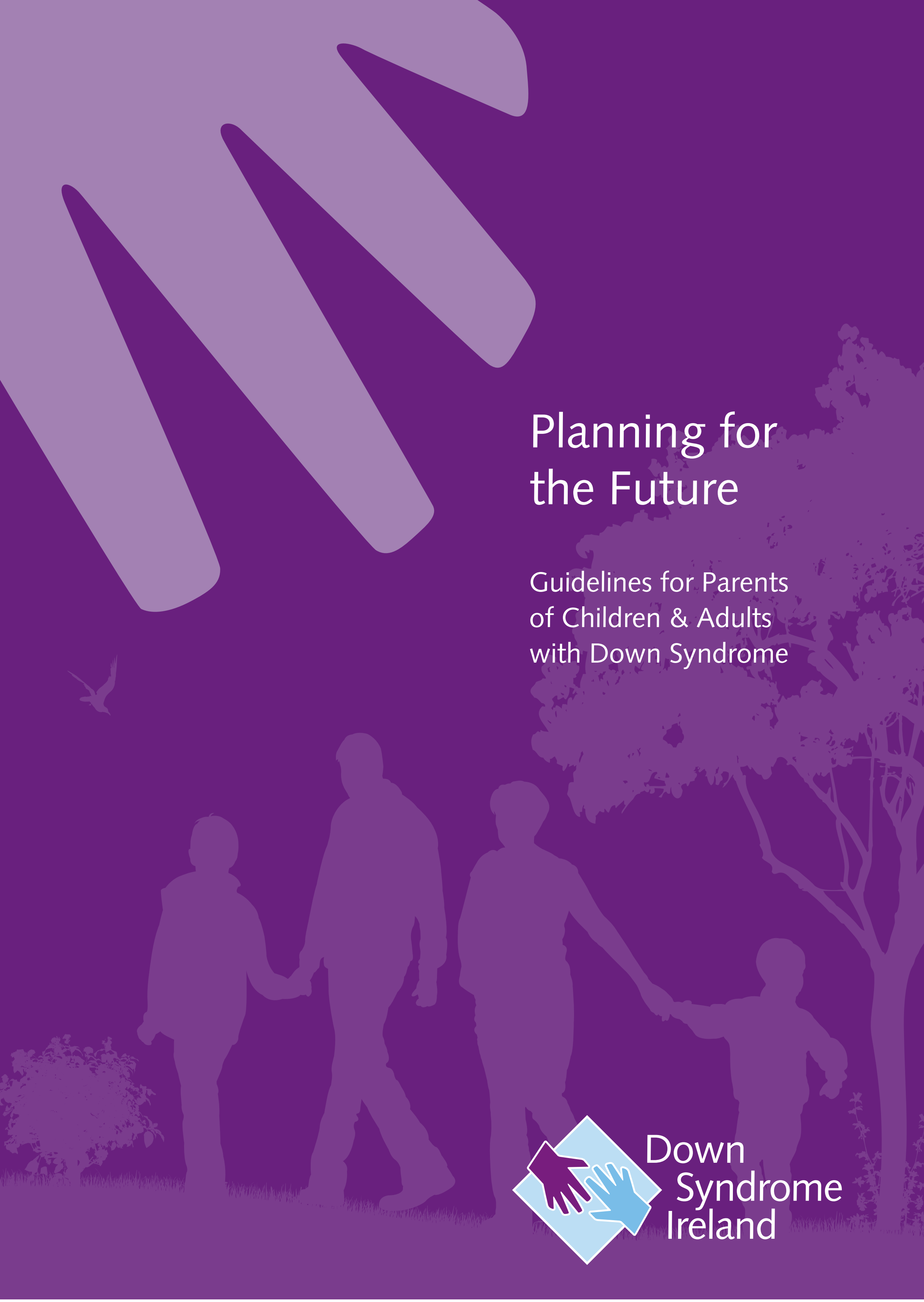

Planning for the Future

Guidelines for Parents of Children & Adults with Down Syndrome

Down
Syndrome
Ireland

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ABOUT THE AUTHORS

TADGH KELLY is a Solicitor with Dublin based Law Firm, Pearts Solicitors located at 24/26 Upper Ormond Quay, Dublin, who have been serving their clients in all areas of law for the past 126 years.

Tadgh primarily practices in the area of land disputes, planning law, defamation law and personal injury claims.

Of particular interest to him is the area of law surrounding how best to protect and cater for the needs of people with Down syndrome and he has developed a growing practice in this area based on his particular experience and expertise.

GRÁINNE MURPHY is Down Syndrome Ireland's Independence Officer. Gráinne provides information and advice to people with Down syndrome and their families through local and national seminars that promote the objectives of independence and future planning. Gráinne also delivers seminars and workshops on the topics of disability rights, political awareness and sibling relationships.

Gráinne is heavily involved in lobbying and campaigning in relation to health, education and employment on behalf of our members at National and European level. She engages in research and collaboration with several European Down Syndrome Associations. She is the Irish project manager of the My Opinion, My Vote project

Gráinne is a speech and language therapist by profession and prepares language accessible documents for both Down Syndrome Ireland and external bodies. Gráinne is also the founder and manager of the Irish Down Syndrome Speech and Language Therapy Special Interest Group.

Down Syndrome Ireland

A Cháirde,

I am delighted, in my role as President of Down Syndrome Ireland, to be writing the introduction to this booklet. The information in it is I think, long overdue for parents of people with Down syndrome and I hope our members will find it as useful as it has been to me and my family.

I know all too well that for many people, thinking and planning for a time after they have gone is not easy, but as parents and particularly parents of someone with a disability, it is essential.

In earlier years, most of us could have expected to outlive our child with Down syndrome. But with their increased well being and life expectancy this has now become more unlikely. Therefore it is important that we plan as best we can for the sake of our children and their future happiness, well-being and support. It is also important that other family members or close friends or carers who will be looking after or looking out for, our family member after we have gone, know what they wish to do with their life and the direction in which we would like to see them supported in achieving their goals. After all "what good are your plans if no one else knows about them."

There are two parts to this booklet. The first part addresses the important issue of making a will and leaving your son or daughter properly provided for in a way that is both legal and beneficial to their future life.

The second part is about a Letter of Intent which has been drawn up by the Independence Officer here in Down Syndrome Ireland and is something I had never thought of doing, but which makes perfect sense. It ensures that whoever is appointed guardian of your family member with a disability is made aware of the details of their life, both past and present which in turn will help the person in question to deal a little more easily with the great loss of a parent. The trauma of losing such a close family member will be enough for them to cope with without having the detail of their daily lives totally disrupted as well. As we all know, it is the small details of their day to day living that matter a lot to very many of our family members.

None of us like to think too much about our own mortality. Equally perhaps, we might be afraid of not putting in place an ideal plan for after we have gone. The only worse thing than not having the ideal plan is having no plan at all. The great thing about making a Will and also writing a Letter of Intent is that both can be amended or changed at any stage to keep up with changing circumstances within the family.

So please, if you have not yet made your will or it needs changing to provide for your family member, do it now, not next week or next year, and that goes for all of you whether eighteen or eighty or any age between who has someone with an intellectual disability and has yet to make provision for them.

Le gach dea ghuí,

Claire Leonard

President, Down Syndrome Ireland.

SECTION 1

Will Drafting
Estate & Tax Planning

prepared by
Tadgh Kelly,
Pearts Solicitors

Please Note:
Under the law a person with Down syndrome or an intellectual disability is referred to as a 'person who lacks capacity'. The three terms are used intermittently throughout this booklet.

This booklet is for general information purposes only and does not purport to represent legal advice.

WHAT IS AN ESTATE?

The term "estate" consists of all the property a person owns or controls. It includes houses, cars, bank accounts, shares, cash, furniture, jewellery, art, and collectibles. It includes all businesses and business interests, life insurance and pension benefits.

It is also important to remember that it includes all debts and obligations owed to others upon your death e.g. an outstanding loan with a bank.

WHAT IS ESTATE PLANNING?

Estate planning covers the transfer of property at death as well as a variety of other personal matters and often involves consideration of inheritance tax issues. The core document most often associated with this process is **your Will.**

WHAT IS A WILL?

A Will is a legal document that allows you to choose who receives your belongings and assets after you die.

A Will can also be used to appoint a guardian to look after children until they reach the age of majority (18 years of age).

A Will allows you create a trust which facilitates the transfer of your assets to a family member or relative if you need to make provision into the future for a child who lacks capacity and who, as a result, may be unable to manage their own affairs into the future.

A Will can also avert any possible family disputes and costly court battles that may arise when a person dies without a Will.

SHOULD I MAKE A WILL?

Everyone should have a Will. A Will is the only way you can tell others how you want your assets to be distributed after your death.

Even if you only own a few assets, it is worth making a Will so that you can control what happens to those assets after you die. A Will also allows you to choose a person to manage the distribution of your assets. This person is called an **executor.**

WHO AND WHAT IS AN EXECUTOR?

An executor is a person nominated by you to work under the guidance of your Solicitor to extract a grant of probate which is a licence granted by the High Court allowing the executor to take over your assets and pass them to the beneficiaries of your Will in accordance with your wishes. An executor also makes sure taxes are calculated, necessary forms are filed and tax payments made (your solicitor will guide the executor through this process).

It is recommended that you nominate two executors in your Will in case one is unable to act at the time the grant of probate needs to be extracted.

WHAT HAPPENS IF I DIE WITH NO WILL MADE?

If a person dies without having made a Will that person is said to have died **intestate**, and your estate is distributed by a person called an **administrator** in accordance with the Succession Act of 1965. The administrator assumes the same role as that of the executor as explained above, and the administrator will most often be your spouse or if you have no living spouse then the role of administrator will normally be your closest blood relative such as your son or daughter.

THE LEGAL RIGHT SHARE

Section 109 of the Succession Act of 1965 is designed specifically to avoid the situation whereby a surviving spouse may be disinherited and guarantees that a certain percentage of the deceased spouse's estate will be granted to the surviving spouse. The percentage changes if there is a Will and if there are children of the marriage.

THE LEGAL RIGHT SHARE WHERE THERE IS NO WILL (INTESTACY).

For deaths after 1st January 1967 and where no Will has been made, the assets from your estate will be distributed according to intestacy rules as set down in the Succession Act 1965.

In circumstances where there is a surviving spouse with children, the spouse is entitled to take two-thirds of the estate and the children are entitled to one third of the estate divided equally between them.

In circumstances where there is a spouse and no children then that spouse will take the whole of the estate.

WHY THE PARENTS OF A CHILD WITH DOWN SYNDROME SHOULD ALWAYS MAKE A WILL.

Under the rules of intestacy there is no specific provision made to cater for a child with an intellectual disability and such children are not differentiated from any other child members of the family. As such, the parents of a person with Down syndrome who lacks the capacity to manage their own affairs may not be able to guarantee adequate provision for that child who may need some extra or specifically tailored provision into the future.

It is highly recommended therefore that the parents of a child with Down syndrome should always make a Will no matter how few assets they possess.

LEGAL RIGHT SHARE WHERE THERE IS A WILL (TESTACY).

If there is a Will then the remaining spouse has a right to what is called a "legal right share" of the deceased's estate.

- If there are no children, the spouse is entitled to one-half of the estate;
- If there are children, the spouse is entitled to one-third of the estate, but as discussed in the next section this does not automatically mean that any child or children is/are entitled to the remaining two-thirds of the estate.

If you are a surviving spouse and you find that your deceased spouse has made a Will that does not recognise your legal right share, you may therefore still claim your legal right share. You do not have to go to court; the executor or administrator is obliged to grant you your share.

RIGHTS OF CHILDREN UNDER A WILL

Unlike a spouse, children do not have any absolute right to inherit their parent's estate if the parent has made a Will. Children born inside or outside marriage and adopted children all have the same rights.

However, a child may make an application to court under section 117 of the Succession Act 1965 if he/she feels that he/she has not been adequately provided for. An application must be made within six months of the taking out of a grant of probate (see role of the executor above).

Section 117 of the Succession Act provides that if the court is of the opinion that a parent has failed in his/her moral duty to make proper provision for a child then the court may order such provision be made as it thinks just. In doing so, the court shall consider the section 117 application from the point of view of a prudent and just parent taking into account the position of each of the children and any other circumstances it considers may be of assistance.

The provision is not about equality or fairness between children but rather the applicant child must establish that there was a need for provision to be made for that particular child greater than that made by the deceased either during his/her lifetime or under the terms of the Will.

Any order made by the court under this section cannot affect the legal right of a surviving spouse (one third of the estate where there is a child or children).

I AM A CONCERNED RELATIVE/FRIEND AND I FEAR THAT A PERSON WITH DOWN SYNDROME HAS BEEN DISINHERITED OR TREATED LESS FAVOURABLY THAN OTHER CHILDREN?

A child with Down syndrome may be considered to be perhaps more deserving of an extra proportion of an estate, in that their needs may be greater than other siblings who may progress to third level education or directly enter the work place and commence fending for themselves.

A child with Down syndrome may not be in a position to go to a solicitor and give the necessary instruction in order to commence a legal challenge to a Will in accordance with section 117.

In such instances, the law allows the case to be brought for the benefit of the person who lacks capacity by what is known in legal terms as a **guardian ad litem.** A guardian ad litem is a person who is granted permission by the High Court to step into the shoes of the person who lacks capacity and mount a court action on their behalf. Very often this person will be a close relative.

Any person wishing to be appointed as a guardian ad litem needs to make a preliminary application in the High Court stating their relationship to the child and formally request the Courts permission to bring a section 117 application on behalf of the person with intellectual disability/Down syndrome.

CAN I LEAVE THAT SHARE OF THE CHILD WITH DOWN SYNDROME TO ANOTHER OF MY CHILDREN ON THE UNDERSTANDING THAT THE EXTRA SHARE IS FOR THE BENEFIT OF THE CHILD WITH DOWN SYNDROME?

It is in no way advisable for a parent to leave, what is termed, **a morally obliged gift** e.g. to have instructed a particular son or daughter that they are getting an extra slice of the estate but the extra slice is to be used for the benefit of the child with Down syndrome.

The danger of morally obligated gifts is that the morally obligated recipient may ignore the wishes of the parents and as such there is no guarantee that the monies will ever be used in the best interests of the child with Down syndrome.

Similarly, if the sibling with the morally obligated gift gets married and subsequently separates or divorces, that gift may be carved up to the benefit of a third party in the separation and/or divorce proceedings.

Furthermore, other members of the family may not be aware of this arrangement and sue the estate for the missing slice for the benefit of the child with Down syndrome or indeed for themselves by way of the section 117 procedure (see above).

HOW THEN DO I BEST CATER FOR THE NEEDS OF THE CHILD WITH DOWN SYNDROME IN MY WILL ?

If a person with Down syndrome has too many assets or too much income, they may not be eligible to receive any or all of their state benefits such as the medical card, disability allowance, free travel etc.

Therefore, if your son or daughter is receiving state benefits that are granted subject to a social welfare means test; it is important to arrange your estate in a manner that will minimise his or her loss of benefits and avoid a wardship committee having control of the inheritance (see below).

For many parents who have a child with Down syndrome, the use of a **trust** is the most effective way to help that individual. The purpose of a trust is to keep assets in a form that will be available to your son or daughter but that will not disqualify them from government benefits for which he or she might otherwise be eligible.

The trust used to achieve this objective is known as a **Discretionary Trust** and it may be incorporated into your Will.

- The person who creates the trust is the settler (i.e. the parent).
- The person who holds the property for another's benefit is the trustee (very often a brother or sister of the child with Down syndrome).
- The person who is benefited by the trust is the beneficiary (the child with Down syndrome).
- The property that comprises the trust is the subject matter (money and land).

HOW DOES THE TRUST OPERATE?

A **Discretionary Trust** is an arrangement whereby property is set aside with directions to your executor that it be used for the benefit of a beneficiary. In this way you pass the legal title of the subject matter to a trusted person whom you nominate in your Will and that person holds the property as the full legal owner but under a legal obligation to use the property/money for the benefit of the child with Down syndrome.

The fact that the legal title to the property is transferred to the trusted person as opposed to the child means that the assets set aside for the child who lacks capacity do not count for means testing in assessing a right to social welfare benefits.

IF MY CHILD IS MADE A WARD OF COURT CAN THE TRUST MONIES BE TAKEN BY THE STATE?

When a person becomes unable to manage his or her assets because of mental incapacity, an application may be made to the High Court for this person to become a **Ward of Court.** The court must make a decision as to whether the person is capable of managing his or her own property for his or her own benefit.

If it is decided that the person cannot manage his or her own property because of mental incapacity, **a committee** is appointed by the President of the High Court to control the assets on the person who lacks capacity.

Since the trustee has legal ownership of the property of the trust, no other person can compel the trustee to use any of the trust property for the beneficiary's advantage. If the child is taken into wardship, the wardship committee, meaning the person into whose care your child is taken, cannot therefore force the trustee to release or spend the monies in a particular way.

CAN I DETERMINE HOW THE TRUSTEES SPEND THE MONIES?

As mentioned above you cannot direct how the monies in a Discretionary Trust are spent, as the trustees are the legal owners and it is their absolute right to apply the monies as they wish for the benefit of the child with Down syndrome. However, you may guide the trustees in terms of how you would wish them to use the monies for the benefit of your child.

HOW DO I PROVIDE GUIDANCE TO THE TRUSTEES?

This is achieved by leaving a **Letter of Intent** with your Will. Such letters are quite usual and are read alongside the Will, though they are not binding on the trustees. The *Letter of Intent* principally sets out the manner in which you would wish the trustees to exercise their powers and discretion, but is not binding on the trustees.

A guide on how to best draft your own *Letter of intent* is outlined in section two of this booklet.

DISCRETIONARY TRUST TAX

The Revenue Commissioners grant an exemption from discretionary trust tax under section 17 of the Capital Acquisitions Tax Acts where the discretionary trust is set up exclusively for one or more incapacitated persons. They define an incapacitated person as one who is **"because of age or improvidence, or of physical, mental or legal incapacity, incapable of managing that individual or those individual's affairs."**

The exemption will only apply where the discretionary trust has been exclusively set up for the incapacitated person and no other persons. It is possible, though, to include as a beneficiary the institution caring for the incapacitated person. If, however, there is an incapacitated child with siblings who are not incapacitated, all children cannot be included as beneficiaries of the trust; a separate trust must be set up for the incapacitated child.

It is important to note that while there may be an exemption from Discretionary Trust Tax; this exemption does not necessarily extend to any taxes that may arise as monies are released from the trust. Your trustees will need to be aware as they administer the trust not to be overly flamboyant in the manner in which the release monies from the trust or the beneficiary might become liable to income tax.

DISCRETIONARY TRUST, DISABILITY ALLOWANCE, THE MEDICAL CARD AND THE FREE TRAVEL PASS

Various methods of calculating eligibility for the above benefits are used by social welfare. However, the Discretionary Trust is a vehicle for holding assets that you wish to be used for the benefit of your child who lacks capacity going forward. The advantage is that your child does not hold the assets legally and as such these assets cannot be computed for the purpose of any means testing criteria for state benefits such as disability allowance, the medical card and the free travel pass.

WHO SHOULD BE MY EXECUTORS AND TRUSTEES?

This is an extremely important decision. Executors and trustees can be the same people. In other words you can appoint the same two people to act both as executors and trustees.

A person will often make a close family member an executor/trustee.
A beneficiary under your Will may be and often is appointed as an executor.
A beneficiary, however, should never be a witness to a Will since being a witness will invalidate the gift.

Persons to be chosen as executors/trustees, therefore, should be trustworthy and capable and you should have confidence in their ability to carry out your wishes as expressed in your Will. Very often you may choose a brother or sister, aunt or uncle of the child with Down syndrome.

When dealing with persons under the age of 18 years one must also consider the question of testamentary guardians, i.e. if you and your spouse/partner die leaving a child under the age of 18 in whose care do you want to leave your child? The appointment of a **testamentary guardian** can be the most important decision of all, since asking someone to take care of your children on your death can be the most onerous request of all.

Appointing a close relative in this role will at least ensure that the children would be reared, preferably together and in a manner which would meet with your approval. Executors and trustees can also be testamentary guardians though in some cases perhaps a spread of responsibility among different people would be advisable.

SHOULD I MAKE MY OWN WILL?

Despite much talk of this in the popular press, the short answer to this question is **never,** when you are making a Will to cater for the needs of your child with Down syndrome. Your Will may be the most important document you will ever sign. It is essential that you be properly advised and that you execute this legal document in the proper format. The drafting of a Will to cater for the needs of a person with Down syndrome, as seen, requires the inclusion of a Discretionary Trust which renders the matter even more complex. The laws governing the format of Wills and Discretionary Trusts are very strict and even a minor divergence from the strict legal requirements can result in your Will and trust being held to be invalid.

If a Will with a Discretionary Trust is invalid then by the Law all you possess will be distributed in accordance with the laws of intestacy and your child with Down syndrome will receive no special provision.

WHAT HAPPENS IF I BECOME MENATLLY UNSOUND BEFORE I DIE, WHAT HAPPENS TO MY ESTATE?

An **Enduring Power of Attorney** is a legal document that you may execute at a time when you are in good mental health. It allows another specially appointed person known as an **attorney**, normally a son or daughter or other close relative, to take actions on your behalf if ever you become mentally incapacitated. If you become mentally unsound and you have not executed an Enduring Power of Attorney nobody will be able to deal with those assets which you hold in your own name and the only way to deal in those assets will be to have you made a ward of court.

The advantage of executing the Enduring Power of Attorney is that it will give you peace of mind that if ever you become mentally unsound then you will have nominated another individual to act on your behalf and as such protect your assets until your death and thereafter your Will and trust will come into play.

HOW MUCH WILL IT ALL COST?

You firstly need to find a solicitor who is actively involved in drafting Wills and trusts to cater for families with a child who lacks capacity and whom you feel has grasped your concerns and desires in terms of making adequate provision for your child with Down syndrome after your death.

In terms of cost, it will depend on the number of consultations with your solicitor, the size of your estate, the tax planning involved and the actual drafting of the Will, Discretionary Trust and enduring power of attorney. Be frank and open with your solicitor in asking for a quote up front and do not be afraid to ask your solicitor if you may spread the cost over a number of weeks or months. Most solicitors will consider such an arrangement on a case by case basis, especially in the current climate.

SECTION 2

The Letter of Intent

prepared by
Gráinne Murphy,
Down Syndrome Ireland

WHAT IS A LETTER OF INTENT?

The purpose of the *Letter of Intent* is to provide personal information about caring for your son/daughter with Down syndrome. The *Letter of Intent* is not a legally binding document, rather it details very practical information about your child. As a parent of a child with Down syndrome, you know better than anyone, your child's needs and desires, likes and dislikes and information relating to the care and services he/she is receiving.

The *Letter of Intent* informs future guardians and trustees of the details of your child's life, both past and present which consequently will help your child deal a little more easily with the great loss of a parent.

WHAT SHOULD LETTER OF INTENT INCLUDE?

A *Letter of Intent* should include information as follows:

- Names, addresses and phone numbers of people who should be contacted in the event of your incapacity or death.
- Your child's family history, as well as names and contact information for family members who have a good relationship with your son/daughter with Down syndrome.
- The names, addresses and phone numbers of close friends who have a good relationship with your son/daughter with Down syndrome.
- Facts relating to your child's medical condition along with names, addresses and phone numbers of those actively involved in your child's medical care.
- Your child's interests, personality traits, likes and dislikes, including the types of social activities your child enjoys.
- Your child's day-to-day routines such as mealtimes, bedtimes, and extracurricular activities.
- Information about your child's education and your hopes and aspirations for future education.
- Information about any paid or volunteer positions that your child had held and/or what types of jobs he or she might enjoy.
- The location of medical records or other important documents.
- Your child's religious beliefs, including where he or she attends religious services, the names of ministers who are familiar with your child and your hopes for his or her religious upbringing.
- The environment in which you would want your child to live as an adult, such as with relatives or in a group home.
- Any other information you believe is relevant to your child's care.

DOES MY LETTER OF INTENT HAVE TO BE IN ANY SPECIFIC FORMAT?

The *Letter of Intent* does not have to be in any specific format. It can be handwritten or typed, although typing it can make it easier to keep it regularly updated as your son/daughter's needs change.

HOW OFTEN SHOULD I UPDATE MY LETTER OF INTENT?

Some of the information contained in the *Letter of Intent* is permanent but much information will change over the years. The letter is therefore, a "living" document, which must be reviewed at regular intervals and revised when necessary.

Once written, it is advisable to revisit your letter once a year, perhaps during the month of your child's birthday. A current copy should be kept with your estate planning documents so that it can be found when needed.

LETTER OF INTENT TEMPLATE

GUIDANCE FOR FUTURE GUARDIANS AND TRUSTEES

The following, although not a legally binding document is intended to be a guide to writing your own *Letter of Intent* or Information Letter to your chosen future guardians and trustees.

Please don't limit yourself to the listed headings and subheading.

Not every item will be applicable to your situation.

This letter should be the "cover" document in a folder containing all relevant information about your son or daughter with Down syndrome.

Remember to sign and date the letter!

FATHER & MOTHER

General Information:

List both parents' full legal names, other names used, PPS numbers, complete addresses, phone numbers for home and work, county, dates of birth, places of birth, city/town/country where raised, fluent languages, religion, race, blood type, number of sisters and number of brothers. Indicate whether or not you are Irish citizens. If available, attach a copy of both birth certificates.

Marital Status:

Indicate the parents' marital status. If they are currently married; list the date of that marriage, the place the marriage took place and the number of children from that marriage. Also list the dates of any previous marriages, names of other spouses, names and birth dates of children from each marriage. If available, attach copies of marriage certificates, birth certificates and divorce papers.

Family:

List the complete names of the both parents' siblings and parents. For those still living, list their addresses and phone numbers, as well as pertinent biographical information. Again, if available, attach copies of all birth and death certificates.

GENERAL INFORMATION ABOUT YOUR SON/DAUGHTER WITH DOWN SYNDROME

Name:

List the full name of your son or daughter with Down syndrome.
List the name he or she likes to be called.

Numbers:

List your child's PPS number, complete address, height, weight, shoe size, clothing size and telephone numbers for home/work/day centre.

More Details:

List your child's gender, race, fluent languages and religion.

Birth:

List your child's date and time of birth, as well as any complications. List your child's birth weight and place of birth, as well as the city/town/country where he or she was raised. Attach a copy of your child's birth certificate.

Siblings:

List the complete names, addresses and phone numbers of all sisters and brothers. Detail which ones are closest to the person with a disability (both geographically and emotionally). Attach all relevant birth, death and marriage certificates.

Other Relationships:

List special friends and relatives (including addresses and phone numbers) that your son/daughter knows and likes. Describe the relationships. These people can play an invaluable role in your child's life.

Guardians:

Indicate whether any guardians have been appointed. List the name, address and phone number of each guardian and indicate whether that person is a guardian of the person or guardian of the estate. Attach copies of all court documents related to any guardianship proceeding. If successor guardians have been chosen, list their full names, addresses and phone numbers. Even if your child has no guardian, it is often wise to state in the letter your wishes about who you want to act as guardian, if one is needed in the future. Make sure you have spoken with them. This information must also be contained in your Will or it will not have any legal effect.

Advocates:

List the people, in order, who you foresee acting as advocates for your child after your death. Make sure you have spoken with them. Elaborate as to, or explain, any special knowledge or experience that these individuals may possess.

Trustees:

Indicate that you have set up a Discretionary Trust for your child and list the full names, addresses and phone numbers of all the trustees.

Representative Payee:

Indicate whether your son or daughter has or needs a representative payee to manage public entitlements, such as the Disability Allowance.

Power of Attorney:

If anyone has a durable power of attorney for property and/or health care for your son or daughter, list the person's full name, address and phone number. Attach copies of the powers and also indicate the location of the originals.

Final Arrangements:

Describe any arrangements that have been made for your child's funeral and burial. List the full names of companies or individuals, their addresses and phone numbers. Also list all payments made and specify what is covered.

In the absence of specific arrangements, indicate your preferences for cremation or burial. Should there be a church service? If so, you may wish to list readings or songs that you have chosen. If the preference is for burial, what is the best site? Should there be a monument?

MEDICAL HISTORY & CARE

Diagnoses:

List the main diagnoses for your son or daughter's condition i.e. Down syndrome, epilepsy, physical disabilities, psychiatric disorder, or an undetermined problem.

Seizures:

Indicate the seizure history of your son or daughter; no seizures; no seizures in the past two years; seizures under control; seizures in the past two years, but not in the past year; or seizures currently. Does anything act as a "trigger" for increased seizure activity?

Functioning:

Indicate your child's intellectual functioning level (include any documented "label" - mild, moderate, severe, profound, undetermined, etc.). If helpful, give actual examples. Give your own opinion as well as that of others.

Vision:

Indicate the status of your child's vision: normal, normal with glasses, impaired, legally blind, without functional vision, etc. List the date of the last eye test and what was listed on any prescription for eyeglasses. Provide the name, address and phone number of your child's eye doctor. Advise how your child tolerates and/or reacts to visits to the eye doctor.

Hearing:

Indicate the status of your child's hearing: normal, normal with hearing aid, impaired, deaf, etc. and any other relevant information.

Speech:

Indicate the status of your child's speech: normal, impaired yet understandable; requires sign language; requires use of communication device; non-communicative, etc. If your child is non-verbal, specify the techniques you use for communication. Provide information on equipment currently used, used in the past, tried but no longer used, etc.

Mobility:

Indicate the level of your child's mobility:
normal; impaired, requires use of wheelchair or other assistance; dependent on wheelchair or other assistance; without mobility, etc. Provide information on equipment currently used, used in the past, tried but no longer used, etc.

Blood:

List your child's blood type and any special problems concerning blood.

Insurance:

List the type, amount and policy number for the medical insurance covering your son or daughter. What is included in this coverage now? Indicate how this would change upon the death of either parent.

Current physicians:

List your child's current physicians, including specialists. Include their full names, types of practice, addresses, phone numbers and the average number of times your son/daughter visits them each year.

Previous Physicians:

List their full names, addresses, phone numbers, the type of practice and the most common reasons they saw your son/daughter. Describe any important findings or treatment. Explain why you no longer choose to consult them.

Dentist:

List the name, address and phone number of your child's dentist, as well as the frequency of examinations. Indicate what special treatments or recommendations the dentist has made. Also list the best alternatives for dental care in case the current dentist is no longer available. Also provide information on how your child reacts to dentist visits and any necessary preparation for the visit.

Nursing Needs:

Indicate your son/daughter's need for nursing care. List the reasons, procedures, nursing skill required, etc. Is this care usually provided at home, at a clinic, or in a doctor's surgery?

Mental Health:

If your child has visited a psychiatrist, psychologist, or mental health counsellor, list the names of each professional, the frequency of visits and the goals of the sessions. What types of therapy have been successful? What types have not worked?

Therapy:

Does your son or daughter go to therapy (physical, speech, or occupational)? List the purpose of each type of therapy, as well as the name, address and phone number of each current therapist. Also list previous therapists and explain why they are no longer being used. What assistive devices have been helpful? Has an occupational therapist evaluated your home to assist you in making it more accessible for your son/daughter?

Genetic Testing:

List the findings of all genetic testing of your child and relatives. Also list the name of the individual and/or organisation performing the tests, address, phone number and the testing dates. Attach documentation.

Immunisations:

List the type and dates.

Diseases:

List all childhood diseases and the date of their occurrence. List any other infectious diseases your son/daughter has had in the past. List any infectious diseases your son/daughter currently has. Has your child been diagnosed as a carrier for any disease?

Allergies:

List any allergies and current treatments. Describe past treatments and their effectiveness.

Other Problems:

Describe any special problems your son/daughter has, such as bad reactions to the sun.

Procedures:

Describe any helpful hygiene procedures such as cleaning wax out of ears periodically, trimming toenails, or cleaning teeth. Are these procedures currently done at home or by a doctor or other professional? What do you recommend for the future?

Operations:

List all operations with the dates and places of their occurrence, name or names of physicians involved, etc. Attach documentation.

Hospitalisation:

List any other periods of hospitalisation your son/daughter has had. List the people you recommend to monitor your son/daughter's voluntary or involuntary hospitalisations and to act as liaison with doctors

Devices:

Does your son or daughter need any adaptive or prosthetic devices, such as glasses, braces, shoes, hearing aids, or artificial limbs?

Medication:

List all prescription medication currently being taken, plus the dosage and purpose of each one. Describe your feelings about the medications. List any particular medications that have proved effective for particular problems that have occurred frequently in the past and the doctor prescribing the medicine. List medications that have not worked well in the past and the reasons why. Include medications that have caused allergic reactions.

OTC:

List any over-the-counter medications that have proved helpful, such as vitamins or anti-dandruff shampoo. Describe the conditions helped by these medications and the frequency of use.

Monitoring:

Indicate whether your child needs someone to monitor the taking of medications or to apply ointments, etc. If so, who currently does this? What special qualifications would this person need?

Procurement:

Does your son/daughter need someone to procure medications?

Diet:

If your son/daughter has a special diet of any kind, please describe it in detail and indicate the reasons for the diet. If there is no special diet, you might want to include tips about what works well for avoiding weight gain and for following the general guidelines of a balanced, healthy diet. You might also describe the foods your son/daughter likes best and where the recipes for these foods can be found, as well as foods to avoid.

HOUSING

Present:

Describe your son or daughter's current living situation and indicate its advantages/ disadvantages.

Past:

Describe past living situations. What worked? What didn't?

Future:

Describe in detail any plans that have been made for your son or daughter's future living situation. Describe your idea of the best living arrangement for your child at various ages or stages. Prioritise your desires. For each age or stage, which of the following living arrangements would you prefer?

- A relative's home (Which relative?)
- Supported living in an apartment or house with supervision
- A group home with other residents
- A private institution (Which one?)
- Parent-owned housing with supervision
- Housing owned by the Discretionary Trust with supervision

Size: Indicate the minimum and maximum sizes of any residential option that you consider suitable.

Adaptation:

Does the residence need to be adapted with ramps or other assistive devices?

Community:

List the types of places that would need to be conveniently reached from your child's home. Include favourite restaurants, shopping areas, recreation areas, libraries, museums, banks, etc.

DAILY LIVING SKILLS

IEP/IPP:

Describe your child's current Individual Education/Programme Plan.

Current Activities:

Describe an average daily schedule. Also, describe activities usually done on "days off."

Monitoring:

Discuss thoroughly whether your child needs someone to monitor or help with the following items:

- Self-care skills (personal hygiene/dressing).
- Domestic activities like housekeeping, cooking, shopping for clothes, doing laundry, or shopping for groceries and cleaning supplies.
- Transportation for daily commuting, recreational activities and emergencies.
- Social activities with others.

Care Givers' Attitudes:

Describe how you would like carers to treat matters like sanitation, social skills (including table manners, appearance and relationships with the opposite sex). What values do you want carers to demonstrate?

Self-Esteem:

Describe how you best reinforce your son or daughter's self-esteem, discussing how you praise and set realistic goals.

Sleep Habits:

How much sleep does your son or daughter require? Does he or she have any special sleep habits or methods of waking up?

Personal Finances:

Indicate whether your son or daughter needs assistance with personal banking, bill payments and budgeting. If so, how much help is needed?

Allowance:

Indicate whether you recommend a personal allowance for your son or daughter. If so, how much? Also, list your recommendations about supervision of how the allowance is spent.

EDUCATION

Schools:

List the schools your child has attended at various ages and the level of education completed in each programme.

Current Programme:

List the specific programme, schools and teachers your son or daughter has. Include addresses and phone numbers.

Academics:

Estimate your son or daughter's academic skills in reading, writing, maths, etc. List any special abilities

Emphasis:

Describe the type of educational emphasis (such as academic, vocational, or community-based) on which your son or daughter currently concentrates. What educational emphasis do you think would be best for the future?

Integration:

Describe the extent that your child has been in mainstream classes or schools during his or her education. What are your desires for the future? What kinds of undesirable conditions would alter those desires?

DAY PROGRAMME OR WORK

Present:

Describe your son or daughter's current day programme and/or job.

Past:

Describe past experiences. What worked? What didn't? Why?

Future:

Discuss future objectives. Prioritise your desires.

Assistance:

Indicate to what extent, if any, your son or daughter needs assistance in searching for a job, in being trained, in becoming motivated and in receiving support or supervision on the job.

LEISURE & RECREATION

Structured Recreation:

Describe your son or daughter's structured recreational activities. List favourite activities and the favourite people involved in each activity.

Unstructured Activities:

What are your child's favourite means of self-expression, interests and skills (going to cinema/theatre, listening to music, dancing, collecting things, painting, bowling, riding a bicycle, etc.)?

Fitness:

If your son or daughter participates in a fitness programme, please describe the type of programme, as well as details about where and when it takes place and who oversees it.

RELIGION

Faith:

List the religion of your son or daughter, if any. Indicate any membership in a particular church. List or indicate your child's involvement.

Clergy:

List any priests/nuns familiar with your son or daughter. Include the names of the churches involved and their addresses/phone numbers. Also indicate how often your child might like to be visited by these people.

Participation:

Estimate how frequently your son or daughter would like to participate in services and other activities of the church. Indicate how this might change over time. Also describe any major, valued events in the past.

RIGHTS & VALUES

Please list the rights and values that should be accorded to your son or daughter. Here are some examples of what you might list.

- To be free from harm, physical restraint, isolation, abuse and excessive medication.
- To refuse behaviour modification techniques that causes pain.
- To have age-appropriate clothing and appearance.
- To have staff, if any, demonstrate respect and to refrain from using demeaning language.

OTHER

Give an overview of your child's life, your feelings and vision about the future. Describe anything else future carers and friends should know about your son or daughter.

Provide information on organisations that have been of help to you, such as support groups, advocacy groups and organisations that might be of help to your Trustees and Guardians. Be sure to provide individual names, telephone numbers and addresses, etc. Describe how these groups have or may have helped you. Likewise, provide information on what groups to avoid, not to use or join and why.

Assets:

List the total assets your child has as of this date. Indicate how those assets are likely to change, if at all in the future. Specify if these assets are in a Discretionary Trust or otherwise.

Cash Income:

List the various sources of income your son or daughter had last year. Include wages, government cash benefits, pension funds, trust income and any other income

Services & Benefits:

List any other services or benefits your child receives.

Gaps:

Indicate whether any services or benefits are needed but are not being received by your son or daughter. Indicate whether plans exist to improve the current delivery of services or to obtain needed benefits.

Expenses:

List all expenses paid directly by your child in various categories, such as housing, education, health care, recreation, vocational training and personal spending. List all expenses paid directly by parents, guardians, or trustees in various categories.

Changes:

Indicate how your child's financial picture would change if one or both parents died. Be sure to list any additional cash benefits to which your child definitely would be entitled. Also list any cash benefits for which your child might be eligible.

YOUR ESTATE PLAN

Documents:

Attach a copy of the cover page and table of contents of your estate plan. Provide full names, addresses and phone numbers of all your professional advisors. Provide the location of your original Will, trusts and related documents, if not included with the letter.

Insurance:

Provide copies of all insurance policies.

FINAL NOTES

Remember to sign and date the letter!

Please be reminded not to limit yourself to the headings and subheadings listed above. Not every item will be applicable to your situation. Some of the information you will include is permanent but much of it will change over the years. The letter is therefore, a "living" document, which must be periodically reviewed and revised when necessary.

Adapted for an Irish population from the template originally prepared by Brian Rubin & Associates

A FINAL NOTE FROM THE AUTHORS

Thinking of the inevitable is a difficult task for parents when they set about making a Will in order to make proper provision for their children.

This task is made even more difficult from an emotional perspective, when you are trying to make provision for a child with Down syndrome. This booklet was designed to give you peace of mind and to ease the burden, as well as providing a guide as to how best to distribute your assets in such a situation.

In order to protect your son's or daughter's eligibility for government benefits at some point in the future and to provide for his or her long-term needs, you may need to consider establishing a special estate plan as outlined in this booklet.

NOTES

NOTES

This booklet specialises in the area of Will drafting and estate and tax planning for the parents of a child who lacks capacity to look after their own affairs and assets into the future.

It provides a firm and basic understanding of the law in this area and demonstrates clearly the need for all parents of such children to make a Will and ensure adequate provision for their child whilst safeguarding their social welfare benefits.

It also provides a clear and concise guide for writing a *Letter of Intent* for future guardians/trustees.

Down Syndrome Ireland

Citylink Business Park,
Old Nass Road, Dublin 12.

T: 01 4266500 / 1890 374 374
E: info@downsyndrome.ie

www.downsyndrome.ie

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