

Financial Information for Parents who have a Child with Special Needs



Introduction

Being a parent of a child with special needs brings great joy, love and challenges to your life. How do I know this?

This is my beautiful niece, Laura, and my brother, Pierce. Laura was born with Down syndrome; this was our family's first introduction into the world of special needs.

It wasn't until years later that I realised the financial pressures put on a family of a child with special needs. It shocked me how hard it was for Pierce, and other parents, to acquire information and professional advice, not only on finance, but on lots of aspects of their child's care.



Laura & Pierce Cathbert

That was when I decided that I wanted to make a difference. I founded Financial Wellbeing in 2008, a company dedicated to Special Needs Trust Planning. It gives me great joy to help ease the financial worries of parents who are raising a child with special needs. This is my way of helping parents who are constantly faced with difficult choices and challenges.

I am confident that this booklet will help you, as it has helped so many other parents. No matter what financial circumstances you find yourself in today, it is crucial that you put a Trust Plan in place to secure your child's future.

The first step in securing your child's financial future is setting up and funding a Special Needs Trust out of entitlements. This will ensure a decent quality of life for your child after you have passed away.

If you have questions, feel free to email **allan@financialwellbeing.ie** or call me direct on 021 482 3635 / 086 335 3013. All queries are dealt with in complete confidence.

I hope this booklet motivates you in creating a brighter and more secure future for your special needs son or daughter.

Wishing you all the best.

Allan M. Cuthbert

Special Needs Trust Planner

1. Maximise Your Entitlements

Some parents unfortunately go through life and never claim all they are entitled to because they assume they have everything in order. I have personally come across parents who have left hundreds, and sometimes thousands of euros behind in unclaimed entitlements.

It falls on parents to uncover all of their entitlements, allowances, grants and tax credits that are available from the Department of Social Protection, HSE and Revenue.

If you fail to claim an allowance in time then unfortunately you can't back claim. Even if the Department of Social Protection agrees that if you had applied earlier, you would have received a payment. It is always worth doing additional research, or obtaining a second opinion, to guarantee you are receiving all entitlements.

Tax – this is where I see parents leaving the most money behind. It is a complex area and depends on your child's disability. It is very likely that you could be claiming additional credits, VAT or DIRT exemptions.

This is where Financial Wellbeing can help you.

For parents who are aware of an entitlement, the next step is applying in the correct way. Today's economic climate has resulted in far greater numbers of parents being rejected for entitlements such as Domiciliary Care Allowance. The main reasons parents are rejected is because they fail to understand on what grounds they are being assessed. Many times parents will go back to appeal decisions on the wrong basis.

The Department of Social Protection are also systematically carrying out reviews of families' current entitlements. This cost saving measure has resulted in additional stress for parents who again need to produce medical reports, documentation and evidence to support their current entitlements.

Again, feel free to contact our office for assistance on applying or appealing a decision from the Department of Social Protection.

I have personally compiled a comprehensive guide for parents that will give you an explanation of each entitlement. Email **allan@financialwellbeing.ie** to order your free E-Booklet of "A-Z Guide on Special Needs Entitlements".

2. Set Up A Special Needs Trust

Most government entitlements are means tested and only available to your child if they meet the criteria. If your child is above the low financial thresholds set by the government, then they will be expected to financially provide for themselves.

Entitlements such as Disability Allowance are critical resources that help to offset your child's daily living expenses. If you jeopardise your child's access to these basic entitlements then your child's financial future can be severely restricted.

The reality is that even if your child has their full entitlements, it is still unlikely that your child will have a decent quality of life. To complicate matter more, any savings, assets, money or inheritance your child has outside of a Special Needs Trust will be means tested.

This is why it is so important to set up and fund a Special Needs Trust.

A Special Needs Trust is a uniquely designed trust which never affects your child's current or future entitlements. The purpose of the trust is to maintain your son or daughter's quality of life when you are no longer around to take care of them.

Parents often believe that they need to contribute to the trust from their own finances. But the reality is that all parents need to do is put away a small percentage of their child's current entitlements for their future.

I have seen many well-funded Special Needs Trust provide the quality of life that all parents dream of for their children. A Special Needs Trust avoids the numerous financial and legal pitfalls that all families eventually fall into.

If you want your child to have a decent standard of living then make sure to set up a Special Needs Trust as early as possible.





3. Create A Special Needs Will

It is rare to come across parents who have correctly set up their will or incorporated the legal issues facing their child with special needs.

A Special Needs Will establishes four important things for you and your special needs child.

It tells the court:

- 1. What share your special child will receive of the family assets.
- 2. Where your child is to live and who will be their Guardians.
- 3. Who will act as Trustees and manage your child's money.
- 4. How your child with special needs is to be cared for in the future.

This will result in your child receiving the money or assets you would like, without them losing their entitlements.

If you haven't set up your will correctly, the courts may get involved and make decisions for you.

Furthermore, the court can make your child a Ward of Court if they believe your child cannot manage their own financial affairs.

They can then decide where your child lives, meaning he or she may not be cared for by those you intended. As you can imagine, the court's intervention may be miles apart from what you as a parent would want for your child.

One question that stops parents from writing a will is, "Who will care for my special needs child when I cannot?"

However, a Special Needs Will can assist you in answering these questions as well as answering vital questions you may have never thought of. Don't fall into the trap of setting up a standard will with your solicitor. These types of wills can carry unnecessary risks and only create issues to resolve when you are no longer alive.

4. Write A Letter of Wishes

You understand your child better than anyone else: what your child's interests are and what makes him/her smile. The core of good open family communication is in writing a Letter of Wishes.

This will document your child's medical history, daily activities, therapists, schools, professionals and doctors. You should also include any behavioural issues, sensitivities, diet issues, etc. - and remember to include your child's hobbies and what they enjoy.

To ensure the next caregiver is given a head start in providing the best care possible for your child, it is critical that you share your Letter of Wishes with them and all close family members.

Issues will arise that may have a substantial impact on your child's future without you ever realising it. One such example would be a well-intended relative leaving money to your child outside of a Trust. A gift could disqualify your child from future entitlements, which may result in the loss of thousands of euros over your child's lifetime. This event, and many other issues, can be avoided by sharing your Letter of Wishes.

The first people to see your Letter of Wishes should be your nominated Guardians and Trustees.

I always encourage parents to have frank conversations with their Guardians and Trustees, with discussions focussing on what your child needs presently and what they will need going forward. Most parents are uncomfortable about having this conversation for obvious reasons but open discussion based on a copy of their Letter of Wishes is very beneficial.

For your child to have a decent quality of life in the future, it is vital that your Guardians and Trustees are fully aware of their responsibilities and how the Special Needs Trust works. They also deserve the opportunity to say 'NO'. As painful as this may be, it is better to know this at the onset because you can search for alternative Guardians and Trustees.

Remember, open communication between all family members is essential to ensure your special child is at the centre of all financial decisions a family takes.

As part of my Special Needs Trust Plan, you will receive a template that will help you get started with your Letter of Wishes.

5. Build Your Own Financial Security

I came across a very upsetting case recently. I had a meeting with a widow whose son, Ted*, is in full time residential care. Due to cutbacks in the charity they have stopped all "non-core activities" and have asked that all residents voluntarily contribute a large proportion of their entitlements to the charity.

What is even more upsetting is that Ted is now back on medication for the first time in 8 years, he receives minimum stimulation and rarely ever leaves his room now. His favourite hobbies have been stopped and his mum is not in a financial position to help him.

Your child with special needs and your own personal financial situation are tied together. By securing your future, you also help to create a much brighter future for your special needs child and the whole family. As you begin planning for the future of your child with special needs, you must also plan for your own financial future.

A basic financial step you need to carry out is to start to save regularly. Personal loans, credit card debts and large mortgages are the main barriers to savings, and we all have them. A range of financial steps need to be put in place if you want to be in a secure position to support your child financially in the future.

This will give you the financial resources to better support the whole family and give you the ability to set up and fund an adequate Special Needs Trust. With the proper plans in place Ted's story doesn't have to be your child's story, instead you can make a difference to the quality of life of your child when the time comes.

(*Names changed for reason of confidentially)



6. Keep Up To Date

It is of the utmost importance that you keep yourself updated on special needs entitlements, finances, legal and disability acts. These areas will affect your child's income, legal rights, access to services and future quality of life.

You will also need to seek the assistant of professional advisors to assist you in putting the proper arrangements in place.

If you don't have a good knowledge of this whole area then you will be unaware if you are receiving good advice or with all the best intentions, the advice could potentially set you back years. Even worse, it might only be obvious when it is too late to rectify. In this situation, you may not have the time or the financial resources to guarantee a decent standard of living for your child.

Again, Financial Wellbeing can help keep you up to date - sign up to our monthly newsletter by sending an email to **dolores@financialwellbeing.ie**.

CASE STUDY:

I had an appointment with a woman, Joanne* who was in her late thirties with a physical disability. Joanne had a number of financial issues she wanted guidance on. The main issue was that Joanne's mother had passed away a few years previously and Joanne inherited a share of the family home outside of a trust.

The Department of Social Protection contacted Joanne and reassessed all her means tested payments. Because Joanne was now over the financial limit, the Department stopped her Disability Allowance which was worth €9,776 per year.

This could have all been avoided if Joanne's mother had set up a Special Needs Trust for Ioanne.

A standard will was written and Joanne only discovered the consequence when she received her money directly in her bank account.

Finding suitably qualified professionals with an expertise in special needs isn't easy and will take some time. You must thoroughly interview your advisors to ensure they have an in depth knowledge of special needs. They must be able to explain everything in plain English and have the expertise to advise you correctly.

(*Names changed for reason of confidentially)



7. Start Planning Today

When is the right time to start planning for your son or daughter's future? We never seem to find the time. Parents are busy with physiotherapy, speech therapy, psychology reports, and doctors' appointments. The list is endless.

Your child's development and future reliance on entitlements is sometimes hard to predict so parents focus all their energy in improving their child's ability to become more independent, and rightly so.

The only issue with this is that parents can fall into the trap of not prioritising a Special Needs Trust Plan. The difficulty with this is that valuable years are wasted and as time ticks by the chances of adequately funding a trust diminishes.

By setting up a Trust Plan to maintain your child's quality of life after you have passed away, will allow you to put the correct steps in place. This will give you great peace of mind and will also benefit the whole family.

You may have enough going on in your life right now and don't have the time to be worrying about Trust Plans for the future or you may think it is only for the rich. However, ask yourself one last question.

Can I afford to put €15 a week of my child's current entitlements away for their future?

Because that's all it takes, with the right plan to create a brighter future.

There are so many circumstances in our special needs world that we have no control over. Special Needs Trust Planning is not one of them. It's up to you to take charge of this situation and get the appropriate guidance to create a secure future for your child.

Action Plan! You now have a very good understanding of the steps you need to take to create and plan the future financial security you wish for your special child. Like everything in life, you now need to act on the information. Please feel free to contact me if you wish to discuss any area of this booklet or if you would like to find out more about a Special Needs Trust Plan™ for your child. Everything is discussed in total confidentiality.

TESTIMONIAL

Allan has given two talks to the members of Laois Down Syndrome on financial planning for children with special needs. Both talks were extremely well attended with a number of parents continuing to make appointments with Allan to develop individual financial plans for their children. Allan is an approachable and helpful person who is meticulous in ensuring that he gives the best advice possible to parents to help them safeguard the financial future of their child with special needs. I would have no hesitation in recommending Allan to anyone who needs guidance in this subject. No parent wants to leave their child without financial security.

Patricia Mulhall

My Motivation

From my experience, it saddens me to know that the future quality of life for people with special needs will significantly deteriorate when their parents pass away. My motivation behind writing this booklet is to raise awareness of the steps parents can take to secure their child's future.

It is my hope that you are better informed from reading this booklet and begin to put a small proportion of your child's entitlement away into a Special Needs Trust, for their future.

Setting up and funding a Special Needs Trust adequately is the most important financial action you can take. This will be a defining factor in the quality of life for your child after you have passed away.

I understand this is an area none of us as parents would like to think about, but I believe it's very important otherwise you are reliant on the government to support your child. It's never too late to start and the earlier you start to fund your child's Trust, the better their quality of life will be.

Allan M. Cuthbert QFA

This booklet was written by Allan Cuthbert a Special Needs Trust Planner. To order Allan's second free E-Booklet "A-Z Guide on Special Needs Entitlements" email dolores@ financialwellbeing.ie or call our office on 021 482 3635.

Allan currently writes monthly articles for charities and parents associations all over Ireland. He provides free information that appears on their newsletters, Facebook pages and websites. This is a great way for organisation to distribute important information around special needs financial, legal and entitlements out to parents.

Allan is a presenter on a radio show regarding financial issues for children with special needs. He also delivers special needs trust planning workshops for charities all over Ireland to inform parents of how to create a brighter future.

If you are part of an organisation that would like to receive the latest special needs articles or you would like to arrange / attend a special needs trust planning workshop, email allan@financialwellbeing.ie or call 021 482 3635 / 086 335 3013.

Special Needs Trust Package

As a parent of a son or daughter with special needs, you must set up and fund a "Special Needs Trust."

This will ensure your child doesn't lose their entitlements and can maintain their quality of life after you have passed away.

SPECIAL NEEDS TRUST PLAN™

- 90-minute consultation to complete your Trust Workbook™
- Guidance on when to set up a Special Needs Trust
- Options on how best to fund your Special Needs Trust
- Advice on Wills to protect your son or daughter's future
- Assistance in completing your Letter of Wishes
- Co-ordinating with your Solicitor to complete your Will & Trust

Plus:

- Assistance in applying for unclaimed entitlements
- Information on changes to your entitlements as your child gets older
- Special Needs Guidance on your personal finances
- 2nd Consultation to present your tailored Special Needs Trust Plan™
- 12-months unlimited email & phone after-care support

Venue – We hold Trust Planning Clinics all over Ireland at different times of the year. For more information contact Dolores on 021 482 3635 or email dolores@financialwellbeing. ie

We hope you enjoy reading our booklet and thank you for taking the time - Allan

Financial Wellbeing has made every effort to ensure the accuracy of the information it supplies, it will not take responsibility for any information which may be incorrect. We recommend you should consult your solicitor and accountant to verify information. Entitlements are only determined by submitting an application to the relevant department.







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