

7 STEPS

*to a Brighter &
more Secure Future*
for your
Special Child



*Information for Parents who have a
Child with Special Needs*



Financial Wellbeing
SPECIAL NEEDS TRUST PLANNING

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Gillian & Keane Byrne



Aoife Crean



All 3 of us

DOLORES' STORY

I am married with 3 children, David age 22 and twins, Sean & Kate 17. David was born at 28 weeks and weighing in at just under 2lbs. As we were both in intensive care in different hospitals, I did not hold him until he was nearly 3 weeks old. He had suffered a brain haemorrhage, lungs collapsed, skin transparent, not able to take a bottle, lost weight and on a machine to help him breathe. Yet, when eventually I held him, I thought he was the most beautiful baby I had ever seen in my life. My only wish was for him to breathe, as I held him that's what I whispered to him. It didn't matter what the consultants/nurses/doctors told me, I just needed him to live.

I love David as I do all my children, but I do have concerns for the future for him more than my other children. I'm involved in Financial Wellbeing because I feel I can understand parents and want to be there to give parents the knowledge I have in the special needs world. If I can help one person then that's good enough for me.

DAVID'S STORY

I started working with Financial Wellbeing in October 2014. I attend all the workshops and I do the opening and closing formalities. I also helped Allan organise his expenses and I am very good at this. I also ask people to sign up to our free monthly newsletter and get the names and the email address of the people that attended the workshops.

I add these names to the database and I proof read the booklets to check for any spelling mistakes. I organised the sat nav so we could find the venue and I prepare the room for the workshop. I wear my Financial Wellbeing t-shirt. I also import the parents' names and contact details to our database. I like to go for a cup of tea with Allan and Dolores after the workshop and we discuss how the workshop went. I write articles about different things that I find interesting, I hope everyone likes these articles.

ALLAN'S STORY

My niece Laura was born in 2000 with Down syndrome and this was our family's first introduction into the special needs world. 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 my brother Pierce, and other parents, to gather information and professional advice, not only on finance but on lots of aspects of their child's care.

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 additional needs. This is my way of helping parents who are constantly faced with difficult choices and challenges.

I hope this booklet gives you lots of useful information to assist you in creating a brighter and more secure future for your child.

Introduction

When is the right time to start planning for your child's future? We never seem to find the time. We are busy with physiotherapy, speech therapy, psychology reports, the list is endless. Your child's development and progress is hard to predict so parents focus all their energy on improving their child's chances of becoming independent, and rightly so.

The only fear with this is that parents can delay the setting up and funding of a Special Needs Trust. The difficulty with this is that valuable years are wasted and as time ticks by, the chances of success gets smaller.

Parents sometimes make the assumption that the HSE & the government will provide for their child when they have passed away. Again, as HIQA keeps revealing on a regular basis that the system is creaking at the seams. Most of these HSE run residential facilities also charge the residents up to 80% of their weekly Disability Allowance under the Long Stay Charge. Leaving people with little or no money left to support their lives.

There are so many circumstances in our lives that we have no control over. Trust planning is not one of them. It's up to you to take charge of this situation and get the appropriate information and advice. It is our hope that this booklet will help you on this journey.



Allan, David & Dolores



Steps

1. SET UP A SPECIAL NEEDS TRUST

Virtually all government entitlements and HSE services are means-tested and only available for your child if they qualify. If your child is above the low financial thresholds set by the government, then they will be expected to financially provide for themselves.

Entitlements are critical resources that help to offset your child's daily living expenses. If you jeopardise your child's access to these entitlements then your child financial future can be severely restricted. Any savings, assets, money, inheritance or pay-out will all be means-tested.

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. This is why all families are setting up 'Special Needs Trust' and the funds from the Trust will enhance your child future life.

A Special Needs Trust is a uniquely designed Trust which allows you to leave money that will provide for your child without impacting them negatively. By placing money, assets, property in this unique Trust, you will avoid the numerous financial and legal pitfalls that all families eventually fall into. Furthermore, you then nominate people you trust to manage the money and this will protect your child's eligibility for entitlements, housing and medical care.

We have seen many well-funded Special Needs Trust provide the quality of life that all parents dream for their children. If you want your child to have a decent standard of living then make sure a Special Needs Trust is the first action you take.



2. MAXIMISE YOUR ENTITLEMENTS

Some parents, unfortunately, go through life and never claim all they are entitled to because they assume they have everything. We 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 the 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 in most cases 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 getting a second opinion, to guarantee you are not leaving money behind.

Lots of parents have issues with their applications and can often get turned down. The main reasons parents are unsuccessful in their applications is because they fail to understand on what grounds they are being assessed. Many times they will go back to appeal the decision, on the wrong basis. However, there are lots of resources online to assist parents and make the application process smoother.

A new issue which we have only see appear in the last twelve months is that parents, who have had allowances for a number of years, are now being selected for a review. This can lead to parents current payments being reduced and in some cases, they have to refund money to the Department.

Some points to note:

Tax is just one area where we see parents leaving lots of money behind. It is so complex and depends on your child's diagnoses, that most parents find it impossible to get it right. It is very likely that you could be claiming additional credits, VAT relief or DIRT exemptions for your child.

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 can solve these legal issues by establishes four important things for you, your family and your special needs child.

It tells the court:

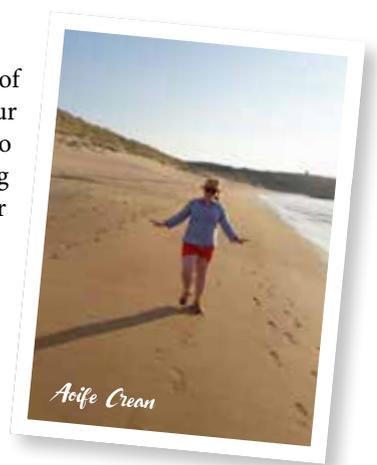
1. How you want to split up your property, assets and money.
2. Where your children are to live and who will be their Guardians.
3. Who will administrate your Will and act as Trustees.
4. How your child with special needs is to be treated.

If you haven't set up your Will correctly, the court can get involved and make decisions for you.

This might result in your child with special needs child not receiving the assets you would like, or notably, they may receive assets that could result in the loss of their entitlements.

Furthermore, the court can decide where your child lives and he or she may not be cared for by those you intended. As you can imagine, the court's vision of what is best for your child may be miles apart from what any parent would want.

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 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. These types of Wills carry unnecessary risks and only create an issue when you are no longer alive to resolve.

4. WRITE A LETTER OF WISHES

You understand your child better than anyone else. What your child's interests are, what makes him/her smile? The core to a smooth transition of care in the future is you writing a detailed Letter of Wishes.

A Letter of Wishes documents your child's family history, daily activities, living arrangements, schools, professionals and entitlements. You should also include any behavioural issues, sensitivities, diet issues, etc. - and don't forget to include your hopes and dreams for their future.

Issues may arise that 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 for your child. 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 with your family.

The first people to see your Letter of Wishes should be your nominate Guardians and Trustees. This ensures the next caregivers are given a head start in providing the best care possible for your child.

We always encourage parents to have frank conversations with their Guardians & Trustees, with discussions focussing on what their child needs will be going forward, and what is expected from them. Most parents are uncomfortable about having this conversation, however, open discussion based on a copy of their Letter of Wishes is very beneficial.

For your child to have a good quality of living in the future, it is vital that your Guardians & Trustees are fully aware of their responsibilities, duty of care and the financial resources available. 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 decisions a family take.



5. HOSPITAL PASSPORT

As you are well aware bringing your child to the hospital can be daunting. All you and the hospital staff want is to make your child better as fast and painlessly as possible.

However, we all know from personal experience that it can be very stressful as you feel you

have so much to tell the hospital staff regarding your child. You may feel that you need to make the hospital team aware of what can upset your child, maybe your child just does not understand “Freddie” is there to help!!

You may also have issues around eating, drinking, sleeping, etc. and the hospital staff want to make the child and the parents as comfortable as possible. With this in mind, we wanted all parents to complete their own personal Hospital Passport.

Your Hospital Passport is a child-friendly way to provide all the information about your child in an easy to read manner. You can provide information on your child’s disability and also on your child’s abilities, other hospitals admissions, medication, health history, down to what your child’s favourite toy is and their favourite food. You should also include the names and contact details of all the professional you are dealing with.

This booklet will stop you having to repeat your child medical history from birth and testing your memory powers when you are stressed. More importantly when you are not by your child side then you know all the staff will be able to familiarise themselves with your child health without having to wait to speak to you. Imagine how much time and stress this is going to save.

Your Hospital Passport is also one of the main documents that you will pass on to your chosen Guardians. This provides them with all the medical information they need to know so they can continue to care for your child. It will make everything easier and you should keep this with your Letter of Wishes.



6. FUNDING YOUR TRUST OUT OF ENTITLEMENTS

By putting away a small amount of your child’s Domiciliary Care Allowance or Disability Allowance on a regular basis over a long period of time, will provide the financial support for your child in the future.

However, as you start to put some money away on a regular bases, it should be noted that the government have placed a few barriers in your way.

Any savings you have in your child’s name will be mean tested when they apply for Disability Allowance, Medical Card, etc. Any saving in the parent’s name will also be mean tested when applying for entitlements such as Carer Allowance. This becomes even more important later in life as most parents qualify for additional entitlements when they retire. Parents should also be aware that all saving and investment policies bring an element of risk to your money and can attract high charges.

Other options are to take out additional life policies. Again the problem with traditional life cover is that it will usually finish before you reach retirement age or when your mortgage finishes. Life cover works on the principle that it is unlikely to ever be paid

out. Some life policies promise to pay out but you will eventually get back less than you put in unless you die prematurely.

The solution for parents of children with additional needs is to take out a specific policy called a Trust Life Policy. This policy is ideal for funding their child's Special Needs Trust because it doesn't impact on anyone's access to entitlements. All parents need to do is pick a term for the policy, either 10/20/30/40-years and how much a week they wish to contribute. The premiums can be taken from the child's entitlements, allowing children to put money away for their own future and getting it back when they most need it when their parents have passed away.



The Trust Life Policy can pay out between 3-6 times what you put in depending on how young your child is when you start. There is no risk to this policy and is not reliant on any external factors such as stock market returns or fund performance, etc. Parent know exactly what their child is getting from the outset and the guarantee minimum pay-outs is €100,000.

A Trust Life Policy is vital when you have a son or daughter with special needs. It will give you the peace of mind knowing that your child will always receive a lump sum of money after your passing that can make a substantial difference to their future quality of life.

7. OPEN A SPECIAL NEEDS BANK ACCOUNT

Most parents find it very complicated to open, operate and manage a bank account for someone with special needs and parents eventually run into numerous issues.



We've had families tell us shocking stories such as, "their son who has an intellectual disability had his bank account cleaned out and his parents were unaware." Banks have also refused to open up accounts for many families as they state that the person with special needs does not understand the terms and conditions. We ask who does!

When speaking to parent we find most parents have fallen into the trap of opening a joint account with their child but this is only a temporary fix and will cause issues when the parent passes away as this account will have to be frozen. An even bigger issue is when the Department of Social Protection is carrying out a means test assessments then all money in a joint bank account can be allocated to either party.

Financial Wellbeing Solution

A Special Needs Bank Account allows both parents to legally manage a bank account on behalf of their child. Having full access to the account then parents can make a decision on their own or jointly with their child, depending on his/her ability to manage their own financial affairs.

From the Special Needs Bank Account, you should pay for your child's medical needs such as any private therapies, equipment, health insurance, hospital, doctors and consultant visits. You should also use this account to pay for your child's personal needs such as phone, hobbies, clothes, entertainment and holidays.

Keep all your bank statements & do not shred them at any stage. These statements will be used when applying for entitlements and will show proof of the financial position of your child.

To open the account a parent needs to complete the application form on behalf of their child and produce two forms of identification. The application form also needs to be signed by your child's doctor.

When opening the account you should also request a laser card, cheque book, standing order forms and direct debit facilities. You must also ask for DIRT exemption to be applied to the account. This will prevent the government taking 39% as a tax on any interest achieved on the account.

OUR MOTIVATION

From our experience, it saddens us to know that the future quality of life for people with special needs can significantly deteriorate when their parents pass away. Our motivation behind writing this booklet is to raise awareness of some of the main steps parents need to take to ensure a good quality of life for their child. Please understand there are lots of aspects which we didn't cover in this booklet.

It is our 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.

We understand this is an area none of us as parents would like to think about, but we believe it's very important otherwise you are reliant on the government and the HSE 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.



WHAT NEXT?

This booklet was written as a guide. We would strongly recommend that you attend one of our Special Needs Trust Planning Workshops to gather more information on:

- How a Special Needs Trust will protect your child's future
- Why a Special Needs Bank Account is necessary
- What to include in your Letter of Wishes
- Understand the importance of a Hospital Passport
- How to choose the right Guardians and Trustees
- Funding options for your Trust that doesn't affect entitlements
- Information on rarely claimed entitlements and tax credits
- How to build financial security for your child

We also have lots of free resource on www.financialwellbeing.ie & remember to connect with us on Facebook.

Take care and thank you for taking the time to read our booklet.

If we can be of any assistance to you and your child then please contact us.

Allan, Dolores & David.

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 that you consult your solicitor and accountant to verify your personal situation.





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