



Down
Syndrome
Ireland

Benefits and Entitlements



Updated: January 2026

Down Syndrome Ireland

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Introduction

Welcome to the Benefits and Entitlements information. This document has been carefully created specifically to address the most frequently asked questions we receive at Down Syndrome Ireland. It is prepared to help you understand the range of benefits and entitlements available to you, providing essential information to assist you in making informed decisions regarding your rights and opportunities.



Purpose of this Document

The purpose of this document is to serve as a comprehensive resource for individuals seeking clarity and guidance on various benefits and entitlements. Whether you are new to the system or looking to better understand your current options.

Our Aim

- Provide detailed information on the types of benefits and entitlements available, eligibility criteria, and the process for accessing them.
- Help demystify complex terms and procedures associated with benefits and entitlements, offering clear explanations and guidance.
- Equip you with the knowledge necessary to make informed decisions that best suit your personal and financial circumstances.

Who Should Use This Document?

This guide is intended for anyone seeking to understand their benefits and entitlements. It can be particularly useful for individuals navigating these options for the first time, or for those who need to stay updated on any changes to existing programs.

How to Use This Document

Each section of this document is designed to address a specific type of benefit or entitlement, outlining the eligibility requirements, application processes, and any other relevant details. We recommend starting with the table of contents to locate the areas most relevant to your needs.

Important Notice

While we at Down Syndrome Ireland strive to provide accurate and current information, it is not a substitute for professional advice. We encourage you to consult with qualified professionals or relevant agencies to ensure that you are fully informed about your specific situation. For further assistance, refer to the contact information provided in the relevant sections.

We hope this serves as a valuable resource in navigating your benefits and entitlements.



Entitlements

Domiciliary Care Allowance

The Domiciliary Care Allowance (DCA) is a monthly financial support program for families caring for a child under 16 with Down syndrome or other disabilities.

Monthly payment

- €380 per month to help with the extra costs of caring for a child with special needs.
- No means test, you don't need to meet any income requirements to qualify.

Carer's Benefit

Carer's Benefit, a financial support program for parents who give up full-time work to care for a child with Down syndrome (or other additional needs).

- Payment to help parents financially while they care full-time for their child.
- Not based on your current income (means-tested).
- Eligibility depends on your past social insurance contributions (PRSI).

Who Qualifies

- A parent who leaves full-time employment to care for a child with Down syndrome or other additional needs.
- You must have been employed for at least 8 weeks in the previous 26 weeks.

Benefits:

- You receive the payment for up to 2 years.
- You can work part-time (up to 18.5 hours per week) and earn up to €625 per week while still receiving the benefit.
- Your weekly payment will be €271 for 1 child/person. €406.50 if you care for more than 1 child/person.

Note: Carer's Benefit is considered taxable income. It's recommended to consult the Citizens Information Board (<https://www.citizensinformation.ie/en/social-welfare/>) for the latest information and to apply.

Carer's Allowance

Carer's Allowance is a weekly social welfare payment for individuals providing full-time care for someone due to their age, disability, or illness (including mental illness). The allowance amount is based on the carer's income, which must be below a specified threshold.

Eligibility

- Must be 18 years or older and be a resident in Ireland.
- Cannot be employed, self-employed, or in education/training for more than 18.5 hours per week.
- Must provide full-time care for someone who:
 1. Is aged 16 or over and needs full-time care for at least 12 months, or
 2. Is under 16 and receiving Domiciliary Care Allowance.
- Must pass a means test.

Means Test:

- Income from various sources is assessed, including cash income, capital (savings, investments, property), and maintenance payments.
- Some incomes are exempt, and certain amount of saving is disregarded.
- The first €450 of weekly income is disregarded for single applicants, and the first €900 for couples. *From July 2026, this will increase to €1000 per week for single applicants and €2000 per week for couples.

Payment Rates (Jan 2026):

- Aged under 66, caring for 1 person: €270 weekly.
- Aged under 66, caring for 2 or more people: €405 weekly.
- Aged 66 or over, caring for 1 person: €308 weekly.
- Aged 66 or over, caring for 2 or more people: €462 weekly.
- Additional amounts for child dependent's: €58 (under 12) and €78 (12 and over) for full rate; half these amounts for half-rate Carer's Allowance.

Care-Sharing:

- Carers can share responsibilities with another carer on a week-by-week basis.
- Both carers must meet all qualifying conditions and will share the allowance and support grants.

Full-Time Care Requirements:

- Providing at least 35 hours of care per week.
- The person being cared for cannot live in an institution, but allowances are made for day care or temporary medical treatment (up to 13 weeks).

Application Process:

Complete and submit the Carer's Allowance application form (CR1), including a medical report signed by the care recipient and their doctor.

Separate forms are needed for each person being cared for if applying to care for multiple individuals.

[Click here for the application form](#)

Additional Information:

- Carers can continue receiving the allowance for up to 12 weeks if the care recipient moves into a nursing home or passes away.
- Carers themselves can take up to 3 weeks' holiday per year without losing the allowance, provided alternative full-time care is arranged.

The Carer's Leave

This allows employees to leave their employment temporarily to provide full-time care. You are entitled to take carer's leave of at least 13 weeks up to a maximum of 104 weeks. If you ask to take less than 13 weeks' carer's leave, your employer may refuse your request.

Carer's leave from employment is unpaid but the Carer's Leave Act ensures that people who want to take carer's leave will have their jobs kept open for them. You may be eligible for Carer's Benefit if you have enough PRSI contributions. If you do not qualify for Carer's Benefit you may qualify for Carer's Allowance which is a means-tested payment.

You can take carer's leave even if you do not qualify for these payments.

To apply for Carer's Leave:

You must have worked for your employer for a continuous period of 12 months.

Note:

While on carer's leave you can take part in employment, self-employment, training or education courses outside the home for up to 15 hours a week.

Household Benefits Package

If you are entitled to Carer's Allowance or Disability Allowance, then you are also entitled to the Household Benefits Package. Only one claimant per household.

• Electricity Allowance of €35 monthly (€1.15 per day)
or
• Natural Gas Allowance of €35 monthly (€1.15 per day)
• Free Television Licence

Note:

The Allowance can be paid if the electricity or gas bill is in your landlord's name. However, you must be living in self-contained accommodation and your landlord will need to confirm, in writing, that you are a tenant and paying your own energy bills.

Free Travel Pass

All people who are in receipt of Disability Allowance, Carer's Allowance, qualify for Free Travel. If you are in receipt of Carer's Allowance, you will have FT (for Free Travel) in the top left-hand corner of your Public Services Card (PSC). Your child with Down syndrome under the age of 16 might not be free.

The letter following it shows who can travel for free with you:

- FT-P - you can travel for free
- FT+S - your spouse, partner or cohabitant can travel with you for free
- FT+C - you can have a person (over 16) travel with you for free

However, children under the age of 16 with a visual impairment are entitled to their own travel pass. Free travel is available on all modes of State public transport and a limited number of private operators.

Carer's Support Grant

Previously known as the Respite Care Grant, the Carer's Support Grant is a tax-free payment made in June of each year for each child/person that you are a nominated carer of. This payment is not means-tested or a taxable source of income. If you work less than 18.5 hours per week or receive Carer's Allowance or Domiciliary Care Allowance, then you can receive this grant automatically, however if you do not receive Carers Allowance and you do not work over 18.5 hours you can apply annually for this payment.

Carers Support Grant Form

Disability Allowance

Disability Allowance is a weekly payment of €254, it is a means-tested payment for individuals aged 16 to under 66 who have a specified disability.

Income and Employment:

- Individuals can work while receiving Disability Allowance.
- The first €165 of weekly income is disregarded, and 50% of earnings between €165 and €375 are also disregarded for the means test.
- Earnings above €375 are fully assessed.

Payment Rates and Additional Benefits:

- Disability Allowance includes a personal rate and increases for qualified adults and children.
- Extra benefits may include Free Travel, Household Benefits Package, and Fuel Allowance.

- Additional increases for living alone, living on a specified island, and other circumstances are available.

Claiming:

- Claimants must complete the [***Disability Allowance claim form \(DA1\)***](#) and provide necessary documentation, including medical evidence.
- Claims are reviewed by Deciding Officers, and decisions are communicated to the claimants.

Note:

As the parents, you will lose your Domiciliary Care Allowance when the person you receive DCA for reaches the age 16 years of age.

Back to School Clothing and Footwear Allowance

All Children in the household are eligible. Each eligible for a child aged 2-11 is €160. Children between the ages of 12-22 (if in full-time education), the payment is €285.

You may qualify for the allowance if:

- Your child is between 2 and 22 (full time education)
- You are getting a qualifying payment from this Department:
 - *Carer's Allowance*
 - *Disability Allowance*
 - *Carer's Benefit* - [Link to full list of Dept Payments.](#)
- You are getting an Increase for a Qualified Child.
- You satisfy a means test.

What are the Income Limits:

Your total household income must be less than €694 for one child. For two dependent children €756, for three dependent children €818, for four children €880. For any dependent child, it will go up by €62. Any savings over €5,000 are also means-tested. If you are not paid automatically, you can apply online from June at [MyWelfare](#).

Fuel Allowance

- Available to those aged 70+ or receiving long-term social welfare/HSE payments.
- €38 per week.
- Paid weekly from September to April (28 weeks).
- €1064 for the season.
- Can be received weekly or in two lump sums (September and January).

Eligibility Criteria:

- Aged 70+ must be legally resident, pass a means test, and live alone or with qualified individuals.
- Under 70 must receive a qualifying social welfare payment and meet all other household composition criteria.

How to Apply:

- Apply Online - The quickest way to apply is through [MyWelfare.ie](https://www.mywelfare.ie).
- Means Test - Your income is considered, if your circumstances remain the same, no need to reapply annually.

Please Note:

Half-rate Carer's Allowance and Disablement Benefit payments are not included in the means test since January 2023.



Tax & Credits

Incapacitated Child Tax Credit

A credit can be claimed by a parent in respect of a child who has Down syndrome. Incapacity by this definition is where a child should grow up and be unlikely to work to support themselves financially.

Claiming the Tax Credit:

Parents or guardians can claim the Incapacitated Child Tax Credit through Revenue's online services such as [myAccount](#), or by completing the relevant claim forms.

Forms Required:

- Incapacitated Child Tax Credit Claim - [Form 1](#)
- Incapacitated Child Tax Credit Claim - [Form 2](#) - Must be certified by a medical practitioner to confirm the child's incapacity.

Additional Information:

- If you have multiple incapacitated children, you can claim a tax credit for each child.
- The tax credit can significantly reduce your tax liability, providing financial relief.

Medical Expenses

Claiming tax relief on Health Expense: you can claim relief on health expenses through [myAccount](#) or the [Revenue Online Services \(ROS\)](#).

Note:

- You can only claim relief for expenses with receipts.
- You can claim relief for health expenses incurred in the last four years.
- Expenses incurred over multiple years must be claimed separately for each year by completing an Income Tax Return.
- Relief is granted via a tax refund, which requires you to have paid tax in the relevant year.
- If you have private health insurance, you can claim tax relief on the portion of expenses not covered by your insurer.

Claiming as a PAYE Taxpayer

Claiming Relief in the Current Tax Year:

- Sign into [myAccount](#).
- Click on the 'Manage your tax 2025' link in PAYE Services.
- Select 'Add new credits'.
- Choose 'Health', then select 'Health expenses', and add it as a credit.
- Complete and submit the form.

Claiming Relief for Previous Years:

- Sign into [myAccount](#).
- Click on the 'Review your tax' link in PAYE Services.
- Request a Statement of Liability.
- Click on 'Complete Income Tax Return'.
- In the 'Tax Credits & Reliefs' page, select 'Health' and then 'Health expenses'.
- Complete and submit the form.

By following these steps, you can efficiently claim your health expense relief through the [myAccount](#) portal.

Home Carer's Tax Credit:

If you're a married couple with children, and one parent stays home full-time to raise them, you might qualify for a tax break. This applies as long as you receive Child Benefit, and the stay-at-home parent earns less than €10,400 annually (excluding Carer's Allowance or Benefit).

VAT Relief

Claiming VAT Back on Aids and Appliances for People with Disabilities

Who Qualifies?

- You must be a person with a disability.
- You (or someone who bought the equipment for you) need to have paid VAT on the purchase.

What can you reclaim VAT on?

- Specialised aids and appliances designed for people with disabilities (e.g. walk-in showers, hoists, handrails).
- Non-specialised items that address your specific needs due to your disability (e.g., some electronic items, sensory aids) with a recommendation from a medical professional.
- Computers for individuals and Tablets/iPad to aid communication.

What can't you reclaim VAT on?

- Services or rentals of equipment.
- Equipment bought by institutions (hospitals, schools, etc.) for general use.

How to claim your VAT refund:

Gather your documents:

- Proof of your disability from a medical professional.
- Original receipts or invoices marked "paid in full" showing:
- Description of the equipment
- Cost excluding VAT
- VAT amount and rate
- Total cost of the equipment
- Supplier details (including VAT number)
- Your details
- Proof of any grants or financial aid received for the equipment (if applicable).

Submit your claim:

- Online through [myAccount](#) (using eRepayments).
- By mail using [Form VAT 61A](#).

Note:

Claims must be submitted within four years of the purchase. The equipment must be used solely by the disabled person.

The Housing Adaptation Grant for People with a Disability

This grant helps people with disabilities modify their homes to be safer and easier to navigate.

What it covers:

- Improved access, ramps, wider doorways, etc.
- Increased space, extensions for downstairs bedrooms, etc.
- Accessible bathrooms, walk-in showers, ground-floor toilets, etc.
- Mobility aids, stairlifts, grab rails, fixed track hoists, etc.

Note:

- The grant doesn't cover VAT on the work, but you can claim VAT back from Revenue for qualifying appliances and their installation.
- Maximum grant, €40,000 or 100% of the cost of work up to €37,500 (whichever is less).
- The amount you receive depends on your household income. Lower income earners qualify for a higher percentage of the cost.

- Local authority discretion, while you may qualify for the maximum grant, it ultimately depends on your local authority's budget.
- Grants are not available for households with a gross annual income exceeding €75,000.

Think you might qualify?

Check with your local authority for details and application procedures. [Click here for the information on Citizens Information.](#)

Local Property Tax (LPT) Relief for Disabled or Incapacitated Individuals

Incapacity meaning where a child should grow up and be unlikely to work to support themselves financially.

Reduction in Chargeable Value:

- Applies to properties adapted to better suit the needs of a disabled person, where the adaptation increases the property's value.

Eligibility Criteria:

- The property must be the main residence of the disabled person.
- The adaptation work must have been done solely to accommodate the disabled person.
- You must have received a grant from a local authority for the adaptation or Revenue approval if no grant was received.

Documents Required:

- Details of the adaptation work, including costs.
- Evidence of the property's chargeable value before and after the adaptation.
- A doctor's certification of the individual's disability and the need for the adaptation.

Full Exemption:

- Applies to properties specifically built or purchased to house a permanently and totally incapacitated person.

Eligibility Criteria:

- The property must be the main residence of the permanently incapacitated individual.
- The property must have been constructed or acquired because it's suitable for the incapacitated person's needs.
- Adaptation work (if done) must exceed 25% of the property's value before the adaptation.

Special Conditions for Individuals Under 16:

- Eligibility is confirmed if a Domiciliary Care Allowance is being paid for the child.
- An occupational therapist's report is required, outlining the child's condition and the necessity of the adaptations.
- [Click here](#) for a document on Properties adapted for occupation by disabled persons.

Tax Relief on Prescribed Healthcare and Aids

You may qualify for tax relief on certain healthcare expenses if they are prescribed by a doctor. These include:

Eligible Healthcare Treatments:

- Drugs and medicines
- Diagnostic procedures
- Physiotherapy or similar treatments
- Chiropody or Podiatry (Foot Treatments)
- Orthoptic Treatments (e.g. for squints and eye movement disorders)
- Home Nursing for a serious illness

Eligible Aids and Devices:

- Hearing Aids
- Orthopaedic Beds or Chairs
- Wheelchairs or Wheelchair Lifts (*Note: Alterations to buildings for lifts are not eligible*)
- Glucometer Machines for Diabetics
- Computers for Individuals with to Aid Communication

Additionally, if you have coeliac disease or diabetes, you can claim tax relief on:

- Gluten-Free foods
- Diabetic products

Instead of a prescription, a letter from a doctor confirming your condition will suffice. You can use receipts from supermarkets or chemists to claim relief.

This list is not exhaustive. Revenue periodically updates the eligible treatments and appliances. If you are undergoing a new procedure or using a new appliance, check with Revenue to see if it qualifies for tax relief.

Note:

You can get a report via loyalty cards from Dunnes and Tesco on how much you've spent on gluten-free foods. This is available in March of each year, and you can use it to claim the money back from the Government.

Homemaker's Scheme

You can claim credits towards your PRSI if you have given up work to take care of your child who has Down syndrome (additional needs). Years spent out of the workforce looking after your child, are credited. Credits are awarded at the same rate as your last paid PRSI contribution. This is crucial to keep up as it will contribute to your future state pension.

Long-Term Carers Contributions (Pension)

Starting January 2024, the Long-Term Carers Contribution scheme will assist full-time carers in qualifying for the State Pension (Contributory). Long-Term Carers Contribution Periods allow carers to qualify more easily for the State Pension (Contributory) by including periods of care in their pay-related social insurance (PRSI) record.

Eligibility

To qualify, a carer must:

- Reside permanently in the State (exceptions for EU or posted workers).
- Be aged 16 or over and under pension age during the care period.
- Not work, volunteer, train, or study more than 18.5 hours a week during the care period.
- Not receive other weekly social welfare payments except for specific allowances. Live with and provide full-time care to an incapacitated person (exceptions apply).
- The person being cared for must require continuous supervision or frequent assistance, with the disability certified by a medical practitioner.

Rates of Payment

There are no direct payments for Long-Term Carers Contributions, but they count towards the State Pension (Contributory) after reaching 1040 weeks (20 years).

Publication on Carers and State Pension

Publication on Long-Term Carers Contributions

Application Process:

- Online Application, available at MyWelfare.ie with a verified MyGovID account.
- Paper Application, for those unable to apply online, contact Pension Caring Supports to request a paper form.

Pension Caring Supports Contact:

Pension Caring Supports

Department of Social Protection,

McCarter's Road,

Buncrana,

Co. Donegal,

F93 CH79

Tel: (01) 471 5898 (or, if calling from outside Ireland, dial +353 1 471 5898)

Lo-call: 0818 690 690

Email: pensioncaringsupports@welfare.ie



Health & Schemes

Free Home Energy Upgrades in Ireland: Get a Warmer, More Efficient Home

The Sustainable Energy Authority of Ireland (SEAI) offers free upgrades to make your home warmer and more energy-efficient. This is especially helpful if you get certain social welfare payments. You must own and live in your home built and occupied before 2006. Your home's energy rating (BER) must be C, D, E, F, or G.

If you receive:

- Disability Allowance
- Domiciliary Care Allowance
- Carer's Allowance (living with the person you care for)

What upgrades are available? (all free)

- Attic insulation
- Wall insulation (cavity, internal, or external)
- Draught-proofing
- Lagging jackets
- Energy-efficient lighting
- Energy advice
- Sometimes: new central heating systems and replacement windows (only if walls are insulated and existing windows are single-glazed)

How to apply:

- Check if you qualify online <https://www.seai.ie>
- Apply online or by form (they can send you one)
- SEAI surveyor checks your home (if you qualify)
- SEAI assigns a contractor to do the work
- SEAI inspects the completed work (including a new BER rating)

The whole process takes about 24-26 months.

Note:

SEAI can do a free BER rating if you don't have one. You might need to repay some of the grant if you sell your home within 5 years.

Medical Card

A medical card gives you and your family access to many health services at no charge.

How to qualify:

You can qualify through a means test, considering your income and household finances. Automatic qualification, Children receiving Domiciliary Care Allowance or Disability Allowance automatically qualify for a Medical Card.

Benefits of a medical card:

- Free GP visits (family doctor)
- Discounted or free prescription medications
- Reduced costs for hospital stay and some treatments

GP Visit Card

A GP Visit Card allows you to see your family doctor (GP) for free.

Who qualifies?

- All carers receiving Carer's Benefit or Allowance automatically qualify
- All children under 8 years of age are also entitled to a GP Visit Card

Note:

While GP visits are free, you may need to pay for any prescribed medications.

Long-Term Illness Card

The current medical conditions that qualify under the Long-Term Illness Scheme are:

<ul style="list-style-type: none">• Intellectual disability• Mental illness (for people under 16 only)• Diabetes insipidus• Diabetes mellitus• Haemophilia• Cerebral palsy• Phenylketonuria Epilepsy• Cystic fibrosis	<ul style="list-style-type: none">• Multiple sclerosis• Spina bifida• Muscular dystrophies• Hydrocephalus• Parkinsonism• Acute leukaemia• Conditions arising from use of Thalidomide
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Regardless, if your child has a medical card or a GP Visit Card, your child with Down syndrome (additional needs) may still get an individual Long-Term Illness card. This has nothing to do with income, but instead is based on your child's medical condition. This allows your child to get medicines directly related to the treatment of their illness, free of charge.

Discretionary Hardship Scheme

The HSE has a national framework for the administration of Discretionary Hardship arrangements. The hardship scheme is designed to cover medical card holders for the items such as medications, dressing and medical supplies, which are prescribed by a consultant however are not available through the medical card.

How to apply:

- If you live in Dublin, Wicklow or Kildare you can apply via your Local Health Office.
- If you live elsewhere in the country, your first point of call will be local pharmacy.

Free Nappy Scheme:

This scheme provides nappies free of charge to children with Down syndrome (additional needs) who are 3-years old and upwards.

How to apply:

- Contact your Public Health Nurse (PHN).

Disabled Drivers and Disabled Passengers (Tax Concessions)

These regulations provide tax concessions for disabled drivers and passengers, effective from December 1, 1994. The regulations specify medical criteria, certification procedures, and repayment limits for eligible individuals.

Required:

- **Primary Medical Certificate:** Issued by a Director of Community Care and Medical Officer of Health.
- **Board Medical Certificate:** Issued by the Disabled Drivers Medical Board of Appeal upon appeal.

VRT & VAT Reliefs:

Remission/repayment of VRT and VAT on vehicles and adaptation

Maximum Reliefs for Disabled Drivers:

- €10,000 for adapted vehicles
- €16,000 for specific adaptations
- €22,000 for extensive adaptations
- €48,000 for wheelchair-accessible vehicles with adaptations

Maximum Reliefs for Disabled Passengers/Family Members:

- €16,000 for adapted vehicles
- €22,000 for extensive adaptations
- €32,000 for wheelchair-accessible vehicles with adaptations

VRT Relief - Disabled drivers are eligible for VRT relief, with the amount varying based on the level of vehicle adaptation

- €10,000 for adapted vehicles
- €16,000 for vehicles with specific adaptations
- €22,000 for vehicles with extensive adaptations
- €48,000 for wheelchair-accessible vehicles with certain adaptations

VAT Repayment - Repayment of VAT on the cost of a new vehicle and on vehicle adaptations

Road Tax Relief - Exemption from road tax for an eligible vehicle

Fuel Grant - The fuel grant for qualifying vehicles under the scheme is limited to **2,730 litres annually** for a driver or passenger with a disability. **4,100 litres annually** for a qualifying organization that transports disabled persons.

Note:

Upfront payment with later reimbursement. [Click here for more information from Revenue.](#)

Disabled Parking Permit

You can apply for a parking permit to allow you to park in disabled parking spaces in Ireland and the EU if you are a person with restricted mobility or are certified as blind. To apply for a first time Parking Permit, the applicant must submit a completed application under one of the following three eligibility options as outlined in. You can apply through the [Irish Wheelchair Association](#) for a parking permit.

How to qualify for a permit:

- Eligibility criteria of the applicant for a disabled Parking Permit
- Applicant requires to have their Medical Practitioner or Consultant certify their medical and mobility eligibility
- Applicant is a Primary Medical Certificate holder and will automatically qualify for a permit
- Applicant meets blind certification criteria
- It costs €35 to apply and you can apply.

[Click here to apply for a Disabled Parking Permit with the Irish Wheelchair Association.](#)



Bank Accounts

Banking

Joint accounts aren't ideal for someone caring for a person with Down syndrome's money.

Why?

- If you owe money, it could be taken from the joint account, leaving them short.
- Having a lot of money in a joint account could make them ineligible for some government help.
- If you die, the account could be frozen for a while, making it hard for them to access their funds.

Many families find managing a regular bank account for a loved one with Down syndrome challenging. Here's some good news: most banks now offer special accounts designed to help!

Please Note:

As of June 2025, **AIB will no longer open new Person in Care Accounts**. Existing accounts already in operation are not affected at this time. Instead, AIB now offers young people aged 16 to 18 the option to open a **Standard Care Account**, which operates in a similar way to the previous account. However, once the account holder turns 18, AIB will write to inform them that the account must be wound down. At that stage, AIB expects the individual to engage with the Decision Support Services to create a formal Decision Support Arrangement, outlining how they wish to be supported in making banking decisions. Following this process, the young adult will then need to re-engage with AIB to establish a new bank account. This is the most up-to-date information available, and parents will be kept informed of any further updates.

Due to legislation brought in in 2023, all persons should have their own bank accounts and have access to their own finances where capacity allows. Anyone who needs assistance with financial matters should have an agreement registered with the [Decision Support Services \(DSS\)](#).

Saving Issues

Challenges when saving for your child with Down syndrome:

- Benefits Impact: Money saved directly in your child's name can affect their eligibility for government benefits like disability allowance, medical cards, or free travel. This is because these programs often consider assets when determining qualification.
- Caregiver Benefits at Risk, savings held in your own name might also impact your eligibility for caregiver benefits, such as carer's allowance or medical cards.
- Special Needs Trust, this is a legal arrangement that allows a trusted person to manage funds for your child's future needs without affecting their eligibility for government benefits.



Will

Special Needs Will

The purpose of this section is to give you a broad understanding of the legal issues you need to consider prior to visiting your solicitor.

- Will your child be in receipt of a means-tested entitlement in the future?
- A Special Needs Trust
- Your child will be the sole beneficiary of the Trust
- Your Trustee will have access to the Trust on behalf of your child.
- Money in the Trust can only be used for your child.
- It may not impact your child's access to entitlements
- Additional benefits such as tax & levy exemptions.
- Assets in the Trust will maintain your child's future quality of life.

Trustees:

A Trustee will manage the financial affairs of the Trust. They will be responsible for key investment decisions and ensure that all money is spent wisely. You will need to nominate individuals who are good at investing (if this is what is chosen to do with the money) and comprehend financial risk, return, charges and tax. It is recommended to selecting two Trustees.

Decision Support Services (DSS)

Accessing the need for support:

Indicators that support may be needed include difficulty understanding complex information, weighing options, communicating and understanding all implications of your decisions, remembering important details, needing extra time to think, and facing barriers to services.

Levels for decision support:

1. Decision-Making Assistance Agreement, Lowest level of support; the individual still makes decisions with assistance.
2. Co-Decision-Making Agreement, Middle level of support; decisions are made jointly with a trusted person.
3. Decision-Making Representation Order, Highest level of support; decisions are made on behalf of the individual by a court-appointed representative.

Planning for the future:

Individuals can prepare for a time when they might be unable to make decisions by:

1. Advance Healthcare Directive, Planning healthcare and treatment preferences.
2. Enduring Power of Attorney, assigning a trusted person to make decisions regarding personal welfare and financial matters.

Types of decisions needing support:

Personal Welfare Decisions: Choices about health, living arrangements, social life, education, and more. Property and Money Matters: Managing property, investments, debts, taxes, and significant purchases.

Further information and contact:

For more details on decision support arrangements, visit [Decision Support Service](#) or contact their Information Services team by phone, email, or post.

[Click here for an Easy Read Guide on capacity.](#) This guide emphasises that needing support does not diminish an individual's capacity to make decisions and encourages planning and discussion with trusted individuals.



Letter of Wishes

A Letter of Wishes is a document outlining your dreams and aspirations for your child when you have passed away. It is not a legally binding document, unlike your Will. However, it does provide valuable information that can help the next caregivers understand what they can do to give your child a fulfilled life. Nobody knows or understands your child better than you and it is vital that you pass on this knowledge to your child's Guardians and Trustees.

When starting to write your Letter of Wishes, it can be overwhelming to try to cover all the bases.

To help you, we have listed a few areas you should consider:

- Your child's education needs
- Living arrangements both short-term and long term
- Key people in your child's life and relationships you want to be nurtured
- Information on current and future entitlement for your child
- Information on your Special Needs Trust
- Instructions for the Trustee on the proper use of money left in the Trust
- Guidance on what to do when circumstances change

But most importantly, you should document your child's passions, joys, and hobbies (as well as any dislikes and fears), your future aspirations for your child's/adult's life. It is important you don't keep your Letter of Wishes a secret, share it with your family. Meet with your family and/or nominated Trustees and have an open frank conversation about the future, this will allow the family and/or Trustees to ask any questions and air their concerns as well.

You need to send a copy of this document to your Solicitor to ensure it aligns with your Will. It is also very important that you regularly review your Letter of Wishes and update it as circumstances change.

Saving Issues:

Any savings you have in your child's name will be means-tested when they apply for Disability Allowance, Medical Card, Free Travel, etc. Any savings in the parent's name will be means-tested when applying for entitlements such as Carer's Allowance, Medical Card, Fair Deal Scheme, etc. Savings and investments must pay DIRT tax which substantially reducing any interest made.

Investment policies bring an element of risk to your money & can attract high charges such as management fees, commission payments, and levies.



Hospital Passport

As you are 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 that it can be very stressful as you feel you have so much to tell the hospital staff regarding your child.

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 to healthcare staff, so they know all about your child's abilities and needs. This will help them give you better care. Also, ways your person with Down syndrome present when in pain all signs of discomfort, best way to communicate can be documented plus medication, health history, down to what your child's favourite toy is and their favourite food, as well as if there are any things, they are afraid of in hospital. You should also include the names and contact details of all the professionals you are dealing with.

[Click here for the HSE Health Passport information.](#)

This document will stop you from having to repeat your person with Down syndrome's medical history. More importantly, Empowering Individuals with Down syndrome, having a system where they can directly share their health information can be a big confidence booster and promote independence.

This document needs to be updated regularly and when significant changes to your child's health occur.



What is a Trust?

A trust is when a person (the settlor) gives money/property to trustees to hold for the benefit of others (beneficiaries). Trustees legally own the money/property but must act in the beneficiaries' best interests.

Types of Trust:

Bare Trusts

- Trustees hold property for a beneficiary who has full rights to it.
- Often used for minors.
- For tax purposes, the property is seen as belonging to the beneficiary.

Discretionary Trusts

- Trustees decide which beneficiaries receive benefits and how much.
- Used for flexible estate planning, especially for children, disabled beneficiaries, or vulnerable adults.
- Initial and annual taxes apply to the trust's assets.

Fixed Trusts

- Beneficiaries have fixed rights to specific parts of the trust.
- Examples include life interest trusts where income goes to one person and capital to another after death.

Bare Trust

A bare trust is a type of trust where the settlor (the person giving the money) pays money into a trust fund. The trust fund is managed by a trustee (often parents or grandparents) for the benefit of the beneficiary (often children).

Key Features:

- Typically used to gift money to children who are under 18 years old.
- Once money is paid into the trust, it cannot be taken back. The beneficiary becomes the absolute owner of the trust assets.
- The beneficiary is fully entitled to the assets in the trust, meaning they have the right to the money once they reach the age specified in the trust (usually 18/21).

Management of a Bare Trust:

Trustees Role:

- Trustees manage the trust fund on behalf of the beneficiary. This includes investing the money and making sure it is safe until the beneficiary is old enough to take control.
- Beneficiaries' Rights: Even though the trustees manage the money, the beneficiary is the true owner and can demand the assets when they reach the specified age.

Uses of a Bare Trust:

- Commonly used by parents and grandparents to gift money to children in a way that ensures the money is managed responsibly until the child is mature enough to handle it.

In summary, a bare trust is a straightforward, irrevocable way to manage and protect money gifted to young beneficiaries until they are of age to handle it themselves.

Discretionary Trust

A discretionary trust is one where there is no immediate benefit to the beneficiary. The trustees manage and distribute the assets in the trust subject to the powers conferred by the deed or will.

If you are resident, or ordinarily resident, in the State and you set up a Discretionary Trust, you must complete and return to [Revenue Form DT1](#).

The completed form must be submitted within four months of the date you set up the Discretionary Trust. Discretionary Trust Tax (DTT) is payable by the trustees or by an agent acting for the trustees. The following DTT charges apply to trust assets:

- An initial once-off 6% charge applies to the value of all the assets in the trust.
- An annual 1% charge applies on 31 December each year to the value of all the assets in the trust on that date

Fixed Trust

A fixed trust is a trust where the interests of beneficiaries are determined at the trust's creation. These trusts can:

- Allow beneficiaries to enjoy the income or use of the trust assets right away (such as receiving income for the rest of their lives).

- A fixed trust can give someone immediate benefits, like money each month. However, it can also specify who would get other stuff (such as property etc.) and when they can receive it.
- Allow postponement of the vesting of an interest until a beneficiary reaches a certain age.
- Avoid discretionary trust tax provisions.

Ownership in Fixed Trusts:

Parties Involved:

- **Trustee** - Acts as the legal owner of the trust assets. Their name appears on official documents, but they manage the money/property solely for the benefit of the beneficiaries.
- **Beneficiary (singular)** - In this example, the beneficiary is someone with Down syndrome who receives income and support from the trust specifically designed for their well-being.
- **Beneficiaries (plural)** - In a broader sense, beneficiaries are considered the equitable owners for tax purposes. This means they hold the right to receive both the income generated by the trust assets and the remaining capital (the original assets themselves) when the trust terminates.

Key Points:

- The trustee holds legal title, while beneficiaries hold equitable title.
- The wording can be singular or plural depending on the specific trust.
- Beneficiaries have the ultimate claim to the trust's benefits (income and capital).



Conclusion

Thank you for taking the time to review this information on benefits and entitlements, created specifically to address the most frequently asked questions we receive at Down Syndrome Ireland. We hope that the information provided has been helpful in clarifying your rights, options, and the various supports available to you and your family.

Moving Forward:

We understand that navigating benefits and entitlements can be a complex process, but remember that you are not alone. Down Syndrome Ireland is here to support you every step of the way. Should you have any further questions or need personalised advice, please do not hesitate to reach out to us. Our team is committed to ensuring that you have the resources and information you need to make informed decisions for yourself and your loved ones.

Stay Connected:

To stay updated on any changes in benefits, entitlements, or related policies, we encourage you to stay connected with Down Syndrome Ireland through our website, digest, and social media. We are here to advocate for your rights and provide ongoing support as part of our community.

Final Thoughts:

This guide is a reflection of the questions and concerns raised by individuals and families like yours. We hope that by addressing these topics, we have contributed to making this journey a little easier for you. Your feedback is important to us, so please share your thoughts and suggestions to help us continue improving the resources we provide. Thank you for your trust in Down Syndrome Ireland. Together, we can ensure that every person with Down syndrome has access to the support and opportunities they deserve.

Please note:

This document is not exhaustive and will be regularly updated, for more information on your entitlements and benefits, visit [***Citizens Information.***](#)



This issue of Down Syndrome Ireland's Benefits and Entitlements document was last updated in January 2026.