DOWN'S SYNDROME ASSOCIATION

A Guide for Family Carers Planning for the Future

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Planning for the Future – A Social Care Guide for Families of Adults who have Down's syndrome

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Introduction

As parents and family carers, many of us spend decades supporting our son or daughter to live a good, safe and meaningful life. Even when the caring role has become second nature, it is completely normal to feel uncertain about how to plan for the future or when to approach adult social care. For many older carers, the idea of contacting the council can feel emotional, unfamiliar or even daunting. You may have heard mixed experiences from other families or worry about losing control over the support your relative receives.



This resource has been written to give clear, practical guidance about what social care support looks like for adults under the Care Act 2014, and what your rights are as a family. It builds on earlier DSA factsheets for older carers by offering more detailed information about social care processes, assessments and planning. Our aim is to help you understand each step, feel informed, and be confident about the choices available.

Starting to think about the future does not mean anything has to change immediately. Many families find that planning gradually, at their own pace, reduces worry and gives everyone more time to explore options calmly. It can also make later decisions easier, ensuring that support is built around your family member's wishes, routines and personality rather than being rushed in response to a crisis.

Throughout this guide, the focus remains on the person at the centre. The Care Act requires councils to work in a person-centred way, listening carefully to what matters to them, recognising their strengths, and involving family in a meaningful and respectful way. You know your relative best, and your insight is an important part of any planning.

You can take your time with this resource and come back to each section whenever you are ready. There is no single or right path for every family. What matters most is that any future planning reflects your relative's well-being, preferences and hopes, and that you feel supported and listened to throughout

When to Start Thinking About Social Care

Every family reaches the point of thinking about social care at a different time. There is no set age or stage when you must contact the council. What matters most is noticing when additional support could improve life for your family member or help you continue in your caring role without becoming overwhelmed.

Many older carers tell us that they delayed approaching social care because they felt they should continue managing everything themselves, or because they feared that asking for help might lead to unwanted changes. In reality, the Care Act is designed to support families early, not only in times of crisis. You do not need to wait until circumstances become difficult before seeking advice or an assessment.

Social care can help at any stage, including when:

- You feel that you are doing more physically or emotionally than before.
- You are beginning to think about what will happen in the longer term.
- Your family member would benefit from becoming more independent in small steps.
- Routines are becoming harder to manage as you or your partner get older.
- You are concerned about how care would be arranged if there was a sudden change in your health.
- Your family member wants to try new things, meet new people or gain confidence outside the home.



Many carers also find that small changes, such as a few hours of support each week, can make everyday life easier and help everyone feel more secure. Introducing support early gives your family member time to get to know new people, build trust and adjust at a gentle pace.

Beginning the process now simply opens the door to information and choices. It does not commit you to any particular direction. You remain in control, and you can take things as slowly as you wish. Planning ahead is not a sign of giving up, it is an act of care and love that helps protect your family member's future well-being.

Understanding the Care Act

The Care Act 2014 is the main law that explains how adult social care must work in England. It sets out clear duties for councils and strong rights for adults who may need support, as well as rights for their families. You do not need to know the whole law. What matters is understanding the key principles that protect your family member and guide every assessment and plan.

At the heart of the Care Act is the idea of well-being. Councils must always consider what will help a person stay healthy, safe, in control of their life and connected to their community. This includes emotional well-being, relationships, independence, control over daily life and the ability to pursue what makes life meaningful.

The Care Act also requires councils to work in a person-centred way. This means:

- Listening carefully to what matters to your family member.
- Recognising their strengths and abilities.
- Involving you and other people who know them well.
- Making reasonable adjustments so they can express their views.
- Focusing on outcomes that are important to them.

Councils cannot refuse to assess someone simply because they have managed without services for many years or because they live with family. The law makes clear that anyone who appears to have any level of need is entitled to an assessment. This includes adults who have never had support before and adults whose carers have always provided the majority of help.



The Care Act also protects your rights as a family carer. Councils must consider not only what support your relative needs, but also how caring affects your own health, well-being and daily life. You are entitled to a separate carer's assessment that looks specifically at your needs and what would help you continue caring safely and sustainably.

Understanding these principles can make the process feel less daunting. The Care Act is not about taking control away from families. It is designed to make sure that adults with care and support needs, and the people who care for them, receive the right help at the right time, with dignity, respect and choice at the centre.

Step 1. Asking for a Care Act Needs Assessment



A Care Act needs assessment is the starting point for understanding what support your family member may need now and in the future. It is a legal process that every council must follow. You can request an assessment at any time by contacting your local adult social care team and explaining that you wish to ask for a Care Act needs assessment for your relative.

You do not need to wait until anything becomes difficult. The law is clear that councils must assess anyone who appears to have any level of need for care and support, no matter how small those needs may seem and regardless of your financial situation. It does not matter if your son or daughter has lived at home all their life or if they have never had services before. Simply appearing to have needs is enough to trigger the duty.

During the assessment, the council should talk directly with your family member and with you. The purpose is to understand what everyday life looks like, what is working well, what is becoming harder, and what outcomes your relative wants to achieve. The conversation should feel respectful and centred on their strengths, abilities and preferences, not only on what they find difficult.

An assessment is not a test, and it is not something you can fail. It is a conversation to build a picture of the person as a whole. For many families who have always provided support themselves, it can be reassuring for a professional to recognise the important role you play, and the impact caring has had over many years.

The council may carry out the assessment in person, by video, or occasionally by telephone, but they must involve your family member fully. If communication is difficult or your relative needs more time, the council must make reasonable adjustments. This might include meeting in a quiet place, using simple language or breaking the assessment into shorter sessions. If your relative or you would have significant difficulty being involved, the council must provide an independent advocate to help.

Once the assessment is complete, the council must give you a written record that clearly describes your relative's needs, strengths, wishes and outcomes. This record forms the foundation for any future support plan and personal budget.

Asking for an assessment is an important first step, but it does not commit you to any immediate changes. It simply ensures that your family member's needs are recognised and that you have access to accurate information about the support that could help now or in the future.

Step 2. Carers Assessments for Older Parents

Alongside the needs assessment for your family member, the Care Act gives you important rights as a carer. If you provide regular or ongoing support, you are entitled to a separate carers assessment in your own right. This applies regardless of the amount of care you give and even if your relative does not receive services.

A carers assessment looks at how your caring role affects your health, wellbeing and daily life. It recognises that caring for an adult who has Down's Syndrome can be rewarding, but also physically and emotionally demanding, especially as you get older. The purpose is not to judge your caring, but to understand what would help you continue safely and confidently.

During the assessment, the council should talk with you about:



- How caring affects your physical health, for example tiredness, mobility or long-term conditions.
- How caring affects your emotional well-being, including stress or worry about the future.
- Whether you are able and willing to continue caring in the same way.
- The impact on your relationships, social life, work or retirement.
- What support, short breaks or practical help would make life easier.

The law requires councils to consider whether your caring role is sustainable, which means they must look honestly at what you can manage as you grow older and what would help prevent a future crisis. Many older carers say this part of the process feels validating, because it recognises the pressures that may have built up gradually over many years.

A carers assessment can lead to different forms of support, such as respite, support groups, equipment, emotional support or help to plan for the future. It can also be an important opportunity to think about what would happen if your health changed suddenly and how to make sure your family member would be safe and supported.

You can have a carers assessment at the same time as your relative's needs assessment or separately, whichever feels more comfortable. You do not need to wait for a particular stage in life. As with the needs assessment, asking for a carers assessment does not commit you to using services. It simply ensures that your own well-being is taken seriously and that you have the right support to continue caring in a way that feels safe and sustainable.

Step 3. Mental Capacity, Advocacy and Involvement

Every adult has the right to be involved in decisions about their life. The Mental Capacity Act 2005 sets out how councils, health services and families should support people to make their own choices wherever possible. For many older family carers this part of the process can feel worrying, especially if communication is difficult or if past experiences with professionals were not positive. Understanding these rights can help the process feel safer and more respectful.

The starting point is simple. Everyone must be assumed to have capacity to make their own decisions unless there is clear evidence that they cannot do so at that particular time and for that particular issue. Capacity is not all or nothing. A person may have capacity to make many decisions, such as what to wear or what activities they enjoy but need more support with complex decisions about finances or long-term planning.

If your family member needs help to understand information or express their views, the council must make reasonable adjustments. Here are some examples.

- Using plain language.
- Using pictures, objects or easy read information.
- Meeting in a familiar or quiet place.
- Taking more time or breaking discussions into shorter sessions.
- Involving someone who knows the person well and can help them communicate.

A person is allowed to make decisions that others may see as unwise. The Mental Capacity Act is clear that an unwise decision does not mean a lack of capacity. The focus must always be on whether the person can understand, retain, use and communicate the information they need for that specific choice.

If your family member would have significant difficulty taking part in an assessment or planning process, and if there is no one appropriate who can support them, the council must arrange an independent advocate. This ensures that your relative has someone to help them understand the process, express their wishes and challenge anything that does not reflect their views.

If there are times when your family member is assessed as lacking capacity for a particular decision, then any decision must be made in their best interests. This does not mean making the easiest or cheapest decision. It means considering what they would choose if they were able to decide, taking account of their personality, past preferences, values and current feelings. Families play a central role in this. The law requires decision makers to consult with those who know the person well, and your insight must carry real weight.

Understanding these rights can help you feel reassured that your relative will be treated with dignity and respect, and that their voice will remain at the centre of any planning. You are not handing over control. You are helping to create a process that supports your family member to be heard and understood as fully as possible.

Understanding Support Planning and Personal Budgets



After the assessment is completed, the council must bring everything together in a support plan. This is a written document that explains what your family member needs, what outcomes are important to them, and what support will help them live a good and safe life. The plan should be created with your family member and with you, not written separately and given to you afterwards.

Support planning should feel like a conversation, not a form filling exercise. The council should talk with you about what is already working well, what could be strengthened, and what types of support would make the biggest difference.

This may include support with daily living, opportunities to be part of the community, help with social relationships, developing skills, or support to stay healthy and safe. Your knowledge of your relative's routines, preferences and communication style is essential and should guide the plan.

Alongside the plan, the council must give you a personal budget. This is the amount of money the council has calculated is needed to meet your family member's eligible needs. The budget is not a fixed list of services. It is simply the resource that allows you to choose how support will be arranged in a way that reflects your relative's wishes and preferred lifestyle.





There are different ways that a personal budget can be managed.

A Direct Payment

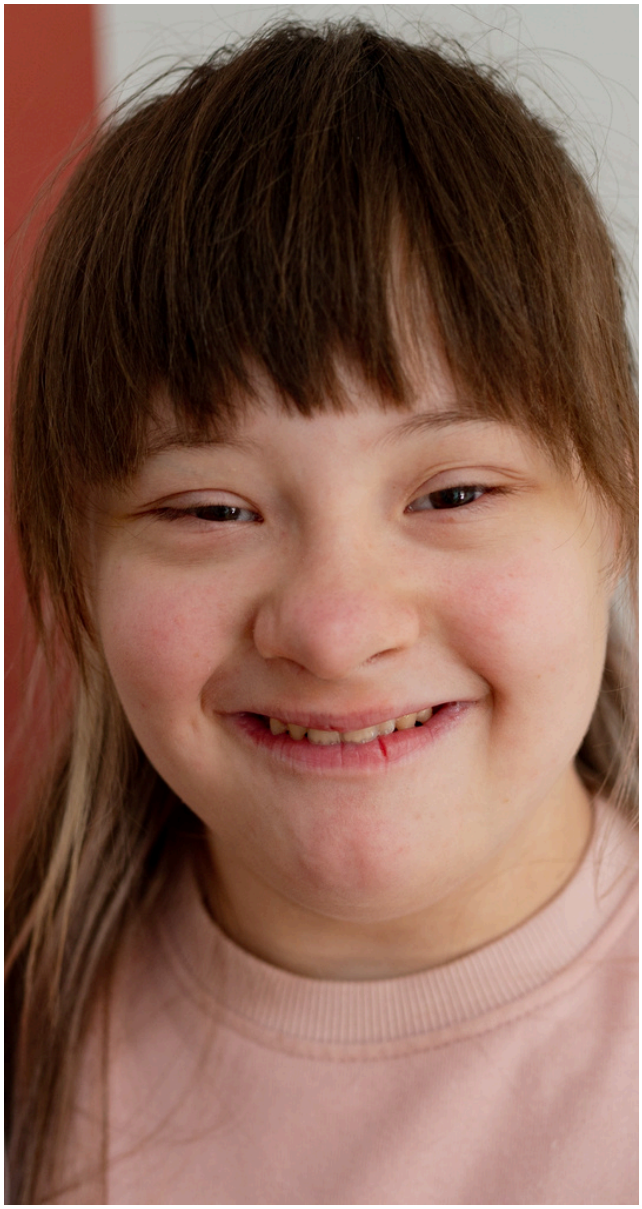
This means the money is paid to your family member or to an agreed representative so that support can be arranged directly. Many families choose this option because it gives flexibility and allows them to employ personal assistants or choose their own support provider.

An Individual Service Fund

In this arrangement a trusted care provider holds the money on behalf of your family member. You still decide how it is used, but you do not have to handle the financial paperwork. It can be a reassuring option for families who want choice and control without taking on payment responsibilities.

A Council Managed Budget

Here the council arranges the support and pays the provider directly. This can work well for some families, especially in the early stages, but you still have the right to be involved in choosing what support looks like.



Many families use a combination of these options over time. You can begin with a council arranged service to get started, then gradually move to a direct payment or an individual service fund as confidence grows. What matters most is that the approach feels manageable and reflects your relative's needs and preferences.

A good support plan should be clear, personal and meaningful. It should describe who your family member is, what is important to them, and what will help them live well now and in the future. You can ask for changes if the plan does not reflect your relative accurately or if it feels too general. The council must take your views seriously and make sure the plan is something you understand and agree with.

Building Support While Still at Home

For many older family carers, the idea of introducing outside support can feel unsettling. You may have cared for your son or daughter for decades and know their routines, moods and preferences better than anyone. It can feel difficult to imagine someone else stepping in or to feel ready for change. The Care Act recognises this and allows support to be introduced slowly, in a way that feels safe and familiar.

Starting small can be one of the most helpful ways to plan for the future. Even a few hours of support each week can give your family member the chance to get used to new people, try new activities, and build confidence at a comfortable pace. This can also give you a short break to rest, focus on your own health, or simply have some time to yourself without worrying.

There are many gentle ways to begin:

- Meeting a personal assistant for short visits or local outings.
- Using a small amount of support to help with community activities.
- Having a support worker join you at home so your relative can get to know them gradually.
- Introducing shared routines, such as cooking, walking or attending a club.
- Building relationships with a provider who may be able to support a future move if your relative chooses.



For people who have Down's Syndrome, consistency and trust make a big difference. Introducing support early means that any future changes can happen with familiar faces and in small steps. Support workers who know your relative well can help them prepare for longer term plans, explore new opportunities, or become more independent over time.

It is also important to remember that bringing in support does not replace your role. You remain the most important person in your relative's life and your knowledge is essential. Many families find that outside support strengthens family life rather than reduces it, because it creates space for enjoyable time together rather than all time being focused on care.

Building support while your relative is still living at home can also help reduce worries about the future. It gives everyone more time to consider different possibilities, and it means your relative will already have trusted people around them if your health changes suddenly or if you need more help in the future.

Taking the first step can feel emotional. It is normal to feel unsure. But beginning gradually allows you to stay in control and make changes only when they feel right for your family.

Thinking About the Future: Housing and Long-term Planning

Thinking about where your family member might live in the future can feel like one of the most emotional parts of planning. Many older carers tell us they worry about what will happen when they are no longer able to provide the same level of support, or when they begin to experience changes in their own health. These feelings are completely natural. The important thing is that you do not have to face these questions alone, and you do not need to make any immediate decisions.

The Care Act makes it clear that adults cannot be moved or placed somewhere against their wishes unless there is a very specific legal reason and a proper best interest's process. Planning for the future is not about the council taking control. It is about helping your family member consider different possibilities and giving you reassurance that safe, appropriate support will be available when needed.

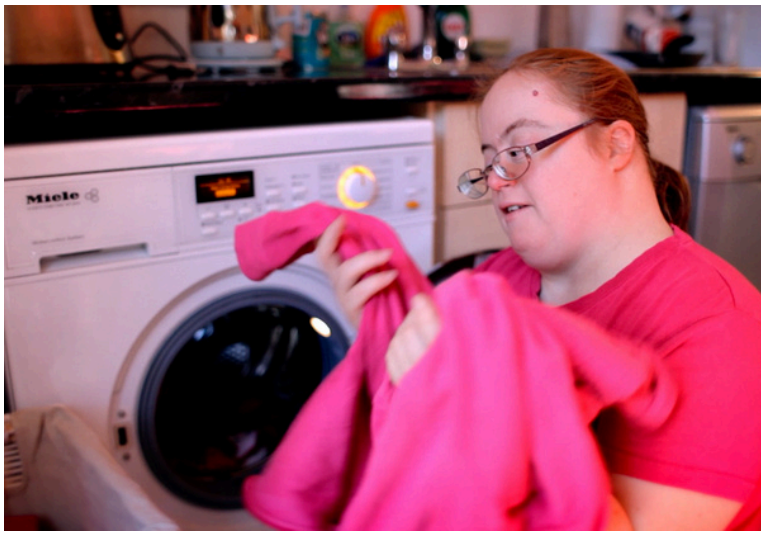
There are several possible housing and support options that families often consider.

Continuing to Live at Home with Family

Many adults who have Down's Syndrome remain at home well into later life. With the right support in place, this can work very well. The key is to make sure that both you and your relative have enough support to stay safe, connected and well.

Moving to Supported Living

Supported living usually means your relative has their own home, often shared with one or two people, with support provided in a way that fits their routine and preferences. This option offers independence and stability, with support that can increase or decrease as needs change. Families often choose this because it gives a sense of home rather than a care setting.



Shared Lives

This is where your relative lives with an approved carer in the carer's family home. Some people find this warm and familiar, especially if they prefer consistent relationships and a quiet environment. It is not right for everyone, but it can be a positive choice for some adults.

Residential Care



Residential care is more structured, with staff available at all times. It may be suitable where someone needs continuous support for health or safety reasons, but it should not be the default option. Under the Care Act the council must consider the least restrictive and most personalised options first.

You do not need to explore all of these at once. It can be helpful to start by thinking about what matters most to your relative. For example, the importance of routine, the need for quiet or stimulation, whether they enjoy company, whether they value privacy, and what helps them feel safe and confident. These things should guide the planning process.

It is also useful to think about your own needs and hopes. Planning early gives you time to introduce support slowly, visit options without pressure, and involve your family member in a calm and positive way. Many families find that early planning reduces fear because it replaces the unknown with clear information and manageable choices.

Long-term planning does not mean making a definite decision now. It means giving yourself and your relative the chance to look ahead with clarity and support, knowing that there is a pathway in place that respects your wishes and protects your family member's future well-being.

Safeguards, Rights and Common Fears

It is very common for older family carers to feel anxious about approaching social care. Many families have heard stories from others or have had past experiences that make them worry about losing control, being ignored or being pressured into options that do not feel right. It is important to know that the Care Act gives strong protections to adults with care and support needs and to the families who support them.

Below are some of the most common fears that older carers share, along with the safeguards that exist in law.

I am worried the council will take over.

The Care Act requires councils to work in a person-centred way. This means your family member's wishes must guide the process. Families must be involved in assessments and planning unless the person clearly does not want this. You are not handing control to professionals. You are inviting them to work with you.

I am afraid my son or daughter will be placed somewhere against their wishes.

No one can be moved or placed somewhere without a proper legal process. A move that goes against a person's wishes can only happen in very limited situations, for example if there is a serious safety risk and the Mental Capacity Act best interests process has been followed. Even then, families must be fully involved, and every less restrictive option must be explored first.

I worry that professionals will not listen to what I know about my relative.

Under the Mental Capacity Act and the Care Act, decision makers have a duty to involve people who know the person well. Your insight into your relative's strengths, routines, behaviours and communication style is essential. You have a right to be consulted and your views must be taken seriously.

I am concerned that getting support means I will be judged.

A needs assessment, or a carers assessment is not an inspection of your home or you're caring. It is a conversation about what would help you and your relative to live well. The aim is to support you, not to criticise. Many older carers find that professionals are respectful and appreciative once they understand the reality of long-term caring.

I worry that services will be taken away later.

Once needs are identified and a support plan is in place, the council cannot reduce support without a lawful review. Any review must involve your family member and you and must clearly demonstrate how needs have changed. Support cannot be removed simply because budgets are tight.

I am frightened about what will happen when I am no longer here.

This is one of the strongest and most painful concerns for older carers. Planning early gives you time to build a stable support network, create a clear plan, and make sure your family member has trusted people around them. Professionals must work with you to put safe arrangements in place and must consider long term sustainability in all assessments.



These safeguards exist to protect adults with disabilities and the families who support them. Knowing your rights and understanding the processes can make the journey feel far less threatening. You do not need to face these fears alone. With clear information, early planning and the right support, families can feel confident that their relative's rights and well-being will remain protected.

Practical Future Planning



Planning for the future does not need to be done all at once. Many older carers find it helpful to take small steps over time, building a clearer picture of what their family member will need and who will be involved. Practical planning can provide peace of mind, reduce worry, and ensure that support continues smoothly if your circumstances change.

Here are some gentle and manageable ways to begin.

Keep Important Information Together

It can be useful to gather key documents in one place so that they are easy to find if needed. This might include assessment letters, health information, medication details, contact details for trusted professionals, and key information about your relative's routines, preferences and communication needs.

Create a Simple Future Plan

Some families choose to write a short letter or document that describes what a good life looks like for their relative. This can include what comforts them, what worries them, what they enjoy, and what helps them feel secure. It does not need to be formal. Its purpose is to help future supporters understand the person quickly and respectfully.

Consider who will be Involved in the Future

If you have other family members, trusted friends or people who are already part of your relative's life, it may be helpful to involve them slowly. This could mean sharing information, inviting them to attend meetings, or helping them understand your relative's needs. Planning early can prevent future pressure on siblings or relatives who may be asked to take on a role without preparation.

Think About Legal Arrangements at Your Own Pace

Some families find it helpful to explore wills, trusts or property planning, especially where a home may one day need to be transferred or managed by others. This resource does not give legal advice, but it can be helpful to seek guidance from an organisation that specialises in planning for disabled adults. You do not need to make every decision now. Gathering information is a good first step.

Introduce Providers or Supporters Gradually

If you think your relative may need more support in the future, beginning with short introductions can make later transitions easier. Meeting a personal assistant for a walk, attending a local activity with support, or visiting a potential provider for a relaxed introductory visit can reduce anxiety for everyone.

Check Emergency Plans

Many families find it reassuring to have a simple plan for emergencies. This might include who would be contacted, what immediate support would be needed, and any essential information about your relative. Councils must consider contingency planning as part of a care and support plan, and you can ask for this to be included.

Practical planning is not about making sudden changes. It is about giving yourself and your family member time, space and clarity. The aim is to build a picture of the future that reflects their personality, your wishes and the legal protections that support you both.

Preparing Emotionally: Planning at the Right Time



For many older family carers, the emotional side of planning for the future is the hardest part of all. You may have spent most of your life supporting your son or daughter, protecting them, and making sure they are safe and loved. Caring becomes part of who you are. It is completely normal to feel worry, sadness, guilt or even a sense of loss when thinking about change, especially if you have been the main source of support for many years.

Letting go does not mean stepping away, and it does not mean that your role becomes less important. Instead, it means allowing other people to share the responsibility so that you can continue being part of your relative's life without carrying everything alone. It means making choices that protect them, rather than responding only when a crisis forces sudden decisions.

Every family reaches this point at a different time. Some parents begin thinking about change when they notice their own health shifting. Others feel ready when they see their son or daughter becoming more confident and wanting to do more independently. Some never feel fully ready but recognise that planning early will make things easier for their loved one later. There is no right way to feel.

Where to get Support

Planning for the future can feel easier when you know where to turn for information, guidance and emotional support. No family should feel that they have to manage everything by themselves. There are organisations, professionals and community groups that can offer help at different stages of the journey.

Below are some places that families often find useful.

The Down's Syndrome Association

The DSA provides information, guidance and emotional support on all aspects of living with Down's syndrome. The helpline is available to answer questions about social care, education, health, future planning and your rights. The website also contains factsheets and resources on a wide range of topics.

Local Adult Social Care Teams

Each council has an adult social care department that can arrange Care Act assessments, carers assessments and support planning. You can contact them directly if you want to request an assessment or ask for advice. They can also offer information about local services, support providers and housing options

Advocacy Services

If your family member needs support to understand information, express their views or take part in decisions, independent advocacy services can help.

Advocates can also support you if you ever feel that your relative's rights are not being fully respected. Your council can tell you which organisations provide advocacy in your area.



Carers Organisations

Local carers centres, community groups and national organisations such as Carers UK can offer advice, support groups, training, and opportunities to meet other carers. These groups can be especially helpful for older carers who want to share experiences with people who understand the demands of long-term caring.



Support Providers and Community Organisations

If you are beginning to explore support options, many providers offer introductory visits or informal conversations. You do not have to commit to anything. These early contacts can help you understand what different types of support look like and what might suit your relative.

Remember that you do not have to do everything at once. Support is available at every stage, and many organisations understand the particular concerns of older family carers. Reaching out for guidance can make planning feel more manageable and can give you the reassurance that you and your relative are not facing the future alone

Summary

Planning for the future can feel overwhelming, especially for older family carers who have spent many years providing love, stability and support. It is normal to feel uncertain, emotional or unsure about where to begin. This guide has been created to help you understand the process at a gentle pace, and to remind you that you do not have to make every decision at once.

The Care Act exists to protect your family member's well-being and to support you as a carer. It ensures that your relative has the right to an assessment, the right to be involved, and the right to support that reflects their wishes, strengths and needs. It also ensures that your own needs as a carer are recognised and taken seriously.

Introducing support gradually can help you and your relative build confidence, reduce worry and explore new possibilities. Thinking about the future does not mean giving up the life you have built together. It means putting plans in place so that your relative can continue to live well, with stability, choice and dignity, even as circumstances change.

You remain the most important person in your relative's life. Your insight and experience carry real weight in any assessment or planning process. Professionals must listen to you, involve you and respect your knowledge.

As you move forward, remember the following:

- You can take things one step at a time.
- You can ask questions at any stage.
- You can request changes if something does not feel right.
- You can involve trusted people gradually.
- You can begin planning early without committing to immediate change
- You are not alone in this process.



Many families find that early planning brings reassurance and creates new opportunities for their relative. It also helps reduce the burden on you, allowing you to enjoy time together without carrying all the responsibility by yourself.

CONTACT US

Down's Syndrome Association

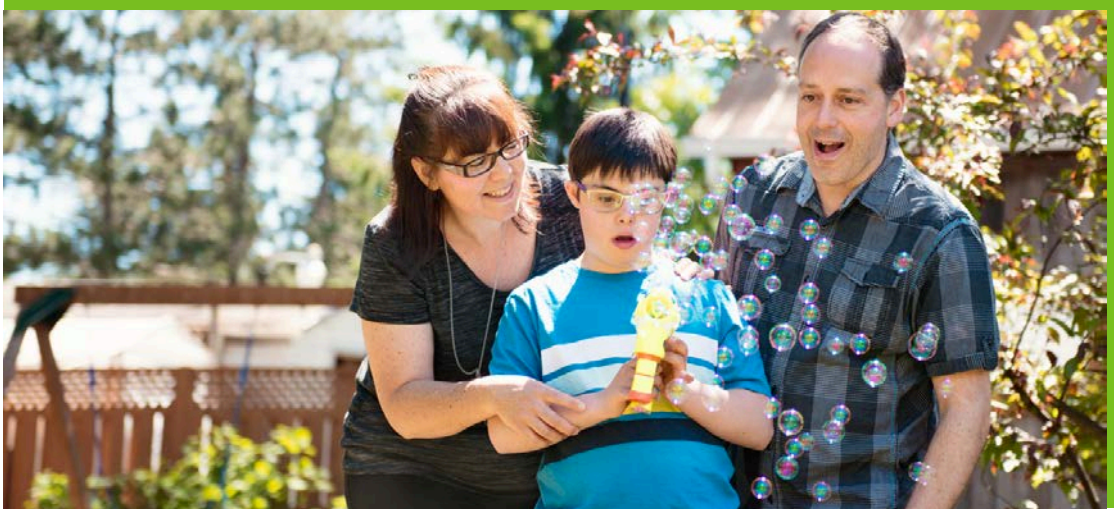
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