



**Down's Syndrome
Association**

A Registered Charity No. 1061474

Supported Living Series



Supported Living:

An introduction for parents and carers

A Down's Syndrome Association Publication

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Who this booklet is for

This resource is a guide for families and carers with a relative thinking about supported living, or who just want to find out more about the options available. It is intended as an overview of the supported living process, from the initial planning and preparation to daily life in your own home.

The guide is part of a series of DSA resources on supported living. Available resources include:

[Easy Read guides for people with Down's syndrome](#)

[A booklet of stories about personal experiences of supported living](#)

[A guide for professionals and support workers](#)

[A video series on life in supported living from people with Down's syndrome, their families and support workers](#)

If you would like more information about supported living, visit the DSA website. You can also contact our Helpline on 0333 1212 300, or email info@downs-syndrome.org.uk



One family explains why they and their son began thinking about leaving home:

“We were keen for our son to be as independent as possible and also had concerns about what would happen to him when we are no longer fit to care for him (or not here to do so). [...] we always had the thought in mind that our son should leave home at about the same age as most children fly the nest, as long as we could get adequate support for him.”

An introduction to supported living

Why move out?

There are many reasons why people with Down’s syndrome start thinking about moving out. These include:

- wanting to have more independence
- wanting their own space
- wanting to be like their peers
- moving out of residential accommodation
- parents are getting older and thinking about the future

Considering living options

There are a number of living options for adults with Down’s syndrome. There is no right or wrong option – what matters is finding what’s right for your relative:

Supported living

Supported living is essentially living in your own home with support. Support is generally offered separately to housing and should provide the person with a greater degree of control over support and daily life.

Residential care

Housing and care are provided together as a package for a person needing support. This generally includes personal care such as assistance with eating, washing and dressing. The Care Quality Commission has a list of registered residential care homes.

Shared Lives

A Shared Lives arrangement is a scheme where a person is matched with a suitable family and lives in their home. The idea behind Shared Lives is to support the person to live in the community in a family setting. Shared Lives carers are paid at a fixed rate and will provide some level of support in the home.

For some people, Shared Lives can be a stepping stone into living in their own home; for others, it is a longer term arrangement. Many Shared Lives schemes are run by local authorities, but some are contracted out to other providers. Your local authority will have information about schemes available in your area.

Intentional communities

Intentional communities are a less well-known living option for people with learning disabilities. Intentional communities are community living arrangements set up for disabled people. The people in the community often share resources and support each other. There are about 50 communities for people with learning disabilities in the UK. The largest and most well-known are Camphill Communities and L'Arche Communities and enquiries or applications can be made directly to them.

Living at home with support

Some adults with Down's syndrome want to continue to live with their family. This is the situation for the majority of adults with Down's syndrome, though increasingly more and more people are looking at other options. If a person wants to live in the family home, additional support can be arranged through adult social care.

You can find more details about this in the support section of this booklet or via the DSA website.

What does supported living look like for people with Down's syndrome?

There is no one single set route into supported living, and it will look different for everyone, for example, some people live in a shared house with other tenants with learning disabilities, whilst others live on their own. What will work for your relative will depend on a number of factors, including individual support needs, what your relative wants out of supported living and what is available locally.

Supported living is not just for people who already have more independent living skills. Those who need higher levels of support can live in their own home, with the right planning and help.



We were lucky to have a very supportive care manager at the time [of planning the move]. There are a lot of things that would have made the first placement better, if we had been listened to and if the procedures had not been quite so bureaucratic.

A parent's experience

Cathy lives in the South East and has a daughter in her thirties in supported living. This is her experience.

Why did you start thinking about supported living?

We started thinking about supported living because we felt that our daughter, like us and her siblings, should move out of the family home around the age of 25. I knew of people in their 70s with sons and daughters in their forties living at home and it was not a satisfactory arrangement. Our daughter also wanted to be independent herself.

How did you plan the move?

We began thinking about it when our daughter went to residential college and started seriously thinking about it when she graduated 3 years later. We read what we could about supported living, and we visited some local schemes.

The move itself took place in two stages. The first lasted 9 months and involved a flat share with another person with Down's syndrome with overnight staff and day support from another agency. There were various problems, but these gave us experience and knowledge about how to and how not to set up the next move.

What problems did you face? How did you solve them?

In the first placement the problems included lack of communication and dissatisfaction with some day to day aspects of our daughter's care and support. The second scheme, which was shared ownership, began with problems finding a suitable flat. This process

took a few months. Once a suitable flat was found the main problems were negotiating how much the local authority would pay for support. Recruitment of care staff was made easy because the local authority contracted an agency which did payroll and recruitment, etc.

What would have made the experience easier?

Less paperwork and more guidance around the maze of housing benefit. As I said, we were very lucky that a Housing Association had offered several flats to people with learning disabilities in the local authority. It was both enjoyable and frustrating house hunting.

We were lucky to have a very supportive care manager at the time [of planning the move]. There are a lot of things that would have made the first placement better, if we had been listened to and if the procedures had not been quite so bureaucratic.

How did you finance supported living?

We were able to pay for the quarter share of the flat, but if we had not been, we could have obtained a mortgage. The three quarters of rent our daughter pays to the Housing Association is paid for by housing benefit, the staff are paid through direct payments and her day to day living costs come from benefits such as DLA and ESA.

What are things like now?

We still have disagreements with the local authority about underfunding and we also get frustrated by the fact that her staff do not do all the things we would do! But this is compensated for by the fact that we all find it a good situation, and our daughter is well cared for.

What is your advice to families thinking about supported living?

Be confident and assertive with professionals because you know your son or daughter best. It should be genuine person-centred planning. You should write down a list of your relative's likes and dislikes, behaviour, routines, etc., to inform the planning and have common sense and compassion as the essential foundation for any scheme.

We hope you found reading this parent's experience helpful. Please keep in mind that this is one experience and it may not be reflective of your situation. What matters is finding what works for you and your family member.



Preparing for supported living

Early preparation

Promoting choice from an early stage can help people with Down's syndrome to get used to the idea of deciding things for themselves. Teenage years can be a good opportunity to encourage choice, even on the basic level of how to spend pocket money and buying clothes and groceries. These small choices can help prepare for bigger life decisions.

Making choices about where to live

The transition meeting in Year 9 is a key time to start thinking about preparing for adulthood and thinking about your relative's hopes for the future, including where to live. However, it is never too late to start considering these questions. Here are some key questions you may wish to consider with your relative to get you started:

- where would you like to live?
- who would you like to live with? Would you like to live on your own, or with friends?
- what do you like to do during the day?
- where do you need to get to/what transport do you need?
- what help do you need to do things you want to do?

Your relative may need support to understand and make a decision. Easy read tools, audio visual resources, images/symbols and adequate time to process information are all useful aids for supporting choice.

A 'talking mats approach' can be helpful for people who have difficulties with communication. The 'talking mats' approach involves using 3 sets of picture symbols with text underneath on a mat. The 3 sets of pictures are topic, options about that topic and how you feel about that option. Your relative can use this approach to select options about different choices, for example, whether to live alone or with friends, etc.

Decision making and mental capacity

Everyone who is part of your relative's life should work from the assumption that he or she can decide where to live. However sometimes, even with support and communication aids, some people are not able to make this decision or communicate their choice.

The Mental Capacity Act (2005) says that it must be assumed that any person aged 16 or above can make decisions unless it can be shown otherwise. This is called assuming that the person has mental capacity. Mental capacity is a person's ability to make a particular decision at a particular point in time. It is assessed on a decision by decision basis; your relative cannot lack mental capacity simply because of a learning disability. Your relative has the mental capacity to make a particular decision if he or she can:

- show some understanding of the information given.
- retain that information long enough to be able to make the decision. Notebooks, photographs, posters, videos and voice records can help people record and retain information.
- weigh up the information and use it to make a decision.
- communicate the decision. This could be by talking, using sign language or other communication aids, blinking or squeezing a hand.

If your relative lacks mental capacity to make a particular decision, a decision will be made on a best interests basis. Anyone interested in your relative's welfare (including family) must be included in this decision making and family members can challenge a decision if they do not believe it is in your relative's best interests. Most disagreements can be easily resolved by good communication between social workers, care staff and families. See the DSA's Mental Capacity Factsheet for more information.

Initial planning and people to contact

Once you have a clearer idea of your relative's wishes, you can start thinking about what to do next. Some things to consider are:

- what does my relative want out of moving home?
- what housing options are available locally?
- are there others in my local area in a similar situation, or who have already been through the process?
- who does my relative want to live with, if anyone?
- what support is needed for all this to happen?
- who needs to be involved?
- what practical arrangements need to be made?

To help you answer these questions, here are practical things you can do in the early stages:

- look at your council's website and find out what they offer adults with learning disabilities.
- search for supported living providers and schemes in your area. The Care Quality Commission has inspection ratings of support providers on their website.
- some local authorities have specific properties for people with learning disabilities who want to live in their own home. If not, your local housing department can tell you about other housing options.
- other local families can provide invaluable peer support and information about local options – a local support group or carers' group can be a good place to start, particularly if there are other families with relatives at the same stage.
- a transition worker can support your relative as they move into adulthood, including looking at where to live. Not every local authority has transition workers – ask your local authority if they offer this service.
- your relative's social worker can support you to plan ahead for leaving the family home. If you do not have a social worker, we suggest that you contact adult social care. They can assess your relative and support you to start planning ahead.
- some local authorities offer a housing brokerage service. A housing broker helps people with learning disabilities explore housing options and find suitable properties. They will work with the family and liaise with different departments, such as the local housing department, private landlords, letting agents, etc. to source a suitable property. Ask your local authority if they offer this service.

Preparing for change

Moving out is a big change for anyone, particularly someone with Down's syndrome. Whilst moving out can be scary, it is a normal part of life with lots of positives, for example, spending more time with friends, having more independence, having your own space, etc.

People with Down's syndrome can have difficulties understanding abstract concepts such as leaving the family home. Providing your relative with examples of people's lives can help. Your relative could talk to older siblings or other family members who have moved out of the family home. Spending brief periods away from family with support can also help people with Down's syndrome get used to the idea of living more independently.

As well as preparing for the change in living environment, it is important that people with Down's syndrome are supported to develop their independence skills before they leave home. Some people attend life skills college courses to develop these skills, though these skills can also be built upon at home.

Developing independence should never mean being left without support. Every person with Down's syndrome is different and some people will need higher levels of support than others. Your relative will probably need at least some level of regular assistance in the home, including prompting and reminding.

Despite the best preparation, there may be an 'adjustment' period when your relative first moves in. Support needs may be greater in these early stages and the support package from the local authority should reflect this.

Contact the DSA
Helpline to talk to
someone about
planning ahead:
0333 1212 300

Older carers and planning for the future

People with Down's syndrome are living longer than ever before, with many people living into their 60s and beyond. This is something to be celebrated, but can also be a source of worry for older carers. You may be starting to worry about the future or finding it increasingly difficult to provide the same level of care and support you used to.

There is no one 'right time' to start planning, as it is different for each family and dependent on individual circumstances. That being said, many families find it helpful to know a plan is in place and that their relative is happy and settled in his or her new home.

Many older adults with Down's syndrome can and do successfully settle into a supported living arrangement. It may take longer for your relative to get used to the change and it may need to take place more quickly, depending on the circumstances. It can be helpful to make enquiries at an early stage about possible housing options and flag up your concerns with your relative's social worker. If you are concerned about your own ability to provide care and support, you can ask your local authority for a carer's assessment in your own right. See the support section of this guide for more information about assessments.

Your own feelings

As well as being a big step for your relative, leaving home can be a conflicting time for families. Whilst you may be happy that your relative is now flying the nest, you may worry about not being able to be there as much as you used to be.

Although there is always a sense of 'letting go', you can still be very much a part of your relative's life and support network. As a parent, carer or family member, you know your relative best. You should be involved in the support planning process as much as possible and support staff should listen to and value what you say.

Reflections from a parent

"Any adult moving into supported living goes through a big transition, emotionally and mentally and to be prepared for this is hard for the adult and also for the parent/carers letting that adult make the move. There is the positive side that it is good that a young person with a learning disability wants independence, but for the parent/carers there is also the vulnerability aspect that needs considering. As parents and carers we have to respect our relative's freedom, but also have to advocate [for them] as their safety and wellbeing is paramount."



Many people with Down's syndrome living in their own homes receive support from support workers in the home.

Getting the right support

Support options

There are several support options for people with Down's syndrome who live independently, including:

- support workers employed by a support provider
- personal assistants hired directly by the person getting support
- support tenants who live with the person and provide daily living assistance as part of an agreement
- circles of support made up of family, friends and individuals interested in the person's welfare, providing an informal support network and speaking up on the person's behalf

Here are some more details about available support options:

Support workers

Many people with Down's syndrome living in their own homes receive support from support workers in the home. Support workers are paid professionals who help with any aspect of daily living, including personal care, cooking, cleaning, getting out and about and managing money.

Support can be provided from a few hours a day up to 24 hours for individuals with the highest levels of need. Support workers are generally provided by private companies and funded via the local authority.

Personal assistants

A personal assistant performs similar tasks to a support worker, but is directly employed by the person he or she supports. Your local authority can provide you with direct payments to fund a personal assistant. You can find more details about direct payments and how to access them later on in this booklet.

There are several ways you can recruit and hire a personal assistant: advertise online, use a personal assistant register or contact a support organisation directly. Before you write your job advert, think about the skills and personal qualities you require. You may like to look at some example personal assistant job adverts for ideas. Skills for Care has further tools for recruiting personal assistants: www.paskills.org.uk

Just like any other job, you will need to interview the candidates and decide who is most suitable. Try to include your relative as much as possible in this process. Your relative will be spending a lot of time with this person, so they both need to get on well. Finding the right candidate may take time, but it is worth persevering to get the right person for the job.

There are a number of benefits to employing a personal assistant. You and your relative can have more control and flexibility over support received and you can choose who to hire. However, you also have an employer's responsibilities and legal obligations. For example, you are responsible for paying their wages, including tax, holidays and national insurance contributions. You do not have to manage these responsibilities alone. See the section on direct payments for details about managing personal assistants.

Some personal assistants say they are self-employed, but it is important to check their official employment status. Contact HMRC's employer helpline for more information: www.gov.uk/government/organisations/hm-revenue-customs/contact/employer-enquiries

Circles of support

A circle of support is a group of people who know your relative well, such as family, friends and supporters. They meet regularly to help your relative achieve what they want out of life. This can include sharing ideas to tackle problems, providing a strong network of relationships, helping your relative feel more independent and taking action to get things done.

Circles of support can add an extra layer of support in addition to paid professionals. There is no formal process to setting one up and you can organise it yourself. See the DSA website for more information.

Support tenants

Support tenants are a less common type of support, but are still a possibility. A support tenant will live with a person with a learning disability and provide some support, such as help with household tasks and budgeting. Support tenants have an agreement that specifies particular duties. This can include being present at certain times of day, offering

assistance with daily living tasks such as preparing meals and notifying the support provider when they will be away. In exchange for support duties, support tenants may not have to pay rent and may receive reasonable expenses for their support duties.

KeyRing is a leading charitable provider of community support networks: www.keyring.org

Support tenants are not technically tenants; they have a licence to occupy, but do not have the same rights as the tenant with a learning disability. This is because it would not be appropriate for a support tenant to have the right to remain in case the arrangement does not work out. The Housing and Support Alliance has more information about support tenancy: www.housingandsupport.org.uk

Community support networks

Community support networks are networks of small numbers of people with learning disabilities living close by. One of the properties in the network is occupied by a volunteer who provides some practical support to each person in that network. The volunteer also supports people in the network to maintain friendships and spend time with each other.

Community support networks are a relatively low support option and people who are part of these networks tend to receive additional help from support workers. Benefits can include helping your relative feel part of a community, promoting independence and providing social opportunities. However, these schemes are not available nationwide and require suitable properties to be available in close proximity to each other. KeyRing is a leading charitable provider of community support networks: www.keyring.org

Planning support

Getting the support right is key to successfully moving into your own home. Start planning ahead by thinking about the tasks your relative will need to do at home and will need help with. This could include:

- cooking meals
- shopping
- handling money/budgeting
- cleaning and tidying
- personal care
- travelling around/using transport
- taking part in leisure/social activities
- getting ready for work/college/going out
- taking medication

Sometimes your relative can do a task, but will need prompting at different stages. This is still something your relative needs support with and must be included in the support package.

See the DSA Social Care guides on assessment for more information.

Accessing support – assessments

Most people have their support funded or provided for by their local authority. You can start this process by asking the adult social care department in your local authority to assess your relative's needs. This used to be called a Community Care Assessment, but is now an Adult Needs Assessment under the Care Act (2014).

Assessments will look at:

- what your relative's needs are
- how those needs affect your relative's wellbeing (quality of life)
- what would happen if your relative did not have any support (e.g. from family or carers)
- what is important to your relative and what he or she wants to do in the future (e.g. live in own home, go swimming once a week, get a job or volunteering, etc.)
- the impact of the person's needs on wider family/carers

Assessments are typically conducted by a social worker and should look at what your relative's needs would be if you weren't around to help and support them. It is important to be realistic during the assessment about what these needs are. Whilst as a parent or carer you will naturally want to highlight your relative's strengths, being honest about the challenges and support you provide will help ensure that the assessor has the right information to make an accurate assessment.

After the assessment, the local authority will decide if your relative is eligible for support and what support is required to meet his or her assessed needs. The majority of people with Down's syndrome will be eligible for support from their local authority, as long as the assessment is done correctly. Having a proper, thorough and balanced assessment is therefore key to getting the right support put in place. It is generally a good idea to prepare prior to the assessment to ensure the person's needs are assessed properly.

Care plans

Once you have had an assessment, a Care Plan will be developed. This should be a detailed document stating how the authority will meet the eligible needs identified by the assessment. It should include:

- support that will be provided
- how the needs of your relative will be met
- when support will be provided, by whom and how often

There is an entitlement to see a copy of the plan and to be asked if you are happy with the content before it is finalised. We suggest that you do not sign off the Care Plan until you are definitely happy with it. You can discuss any concerns with the social

worker and complain if your concerns are not resolved. The plan should be reviewed annually (and more frequently if there is a change in the person's support needs).

You may be told that the care plan needs to go to a panel before it is agreed. Whilst local authorities are allowed to take their financial resources into account, they still have a legal duty to meet your relative's assessed eligible needs. Your local authority must do everything it reasonably can to agree on the care plan with you and your relative. The plan should also be finished in a timely fashion.

Once the plan is finalised, you must be given a copy of the plan. If you don't get a copy, make sure you ask for one as it can help you if you need to challenge anything about the support being provided later on.

Paying for support

After the needs assessment, social services should assess your relative's financial circumstances, using their own financial assessment criteria. They should not take the family or carer's financial circumstances into account when conducting this assessment.

Local authorities fund support in different ways. The local authority can provide support directly as a service. Alternatively, you can also take more control over support by using direct payments.

Whilst many people have their support funded or provided for by local authorities, some people choose to self-fund i.e. pay for support themselves.

Personal budgets and direct payments

Every person who receives care and support from the local authority will have a personal budget. A personal budget is money set aside for a person's support and care, based on assessed needs.

The personal budget should be written on the Care Plan. The money can be used by the person in three different ways:

- services provided or commissioned [purchased from private companies] by the local authority e.g. a day centre
- direct payments
- combination of the two

A direct payment is when you receive your personal budget directly. Direct payments can give you and your relative more control over the support he or she receives. You can support your relative to choose how the money is spent, as long as the local authority agrees that it is meeting his or her assessed needs. For example, you could use direct

payments to pay for a personal assistant to help in the home and take your relative out to places he or she wants to go.

Direct payments can mean more responsibility, as you will have to manage the direct payments. However, you do not have to do this alone. Some local authorities offer an in-house service to help you manage direct payments, including a payroll service for personal assistants. Support brokers, some support providers and certain local voluntary organisations can also support you to manage a direct payment.

If you prefer not to have a direct payment, your local authority can look after your personal budget and organise your relative's support for you. This is typically called a managed budget.

Carers UK has further information about direct payments and how to access them on their website: www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/direct-payments

Disability Rights UK has a specific helpline for personal budgets and direct payments. Find out more on their website: www.disabilityrightsuk.org/how-we-can-help/helplines/independent-living-advice-line



Arranging housing

Renting from a Housing Association or Local Authority

A number of people with learning disabilities rent their home through their local authority or a housing association. Some local authorities have specific properties for people with learning disabilities to rent as part of a package, with support workers visiting the property at specific times. This type of housing tends to be shared with other people with learning disabilities, often between 3 – 5 people.

Renting via your local authority can be one of the most straight-forward options, particularly if there is already an existing service. However, your relative may have less control over who to live with and who provides support. Local provision can also vary. Your local housing department can give you more information.

Renting from a private landlord

Property can be rented from a private landlord. The rent can be paid for by Local Housing Allowance, though this may not meet the full costs. You may be able to find a property more quickly on the rental market, but there is less security of tenancy and contracts are often more short-term.

Shared Ownership

Shared Ownership combines renting and owning a property. This means you part own and part rent a property, usually from a housing association. The share of the home you own ranges from 25% to 75%. Housing Benefit can pay for the part of the home that is rented.

Purchasing a property

Some families decide to purchase a property outright, as it can provide greater control and security over the housing. This depends on individual financial circumstances and being able to locate a suitable property.

If you are unable to purchase a property individually, you may wish to choose to purchase a property jointly with other families. This can reduce costs and provides a support network of families working together. However, such a setup is reliant on knowing local families in a similar situation. You will also need to think carefully about how it will work in practice, for example, planning ahead for the possibility that one of the families involved may withdraw from the arrangement.

Buy to let can affect eligibility for Housing Benefit. See the benefits section on our website or contact our benefits advisers for more information.

Buy to let scheme

Buy to let involves purchasing or building a property, then renting it out. The property can be part of your current property; for example, you could build the property in your garden or extend your current home. The person who owns the property will act as the landlord.

Which option is right for me?

What works will depend on what's available in your area, personal preferences and individual financial circumstances. You can contact your local authority's housing department for more information. You can also find more resources and information on housing options on the Housing and Support Alliance website:

www.housingandsupport.org.uk

Tenancy agreements

People who are renting their own home may need to sign a tenancy agreement. Under the Mental Capacity Act (2005), there should be an assumption that your relative has the mental capacity to decide to sign a tenancy agreement unless it can be shown otherwise. Tenancy agreements can be made accessible (for example, made into Easy Read), so your relative understands the content of what is being signed.

If your relative lacks the mental capacity to sign a tenancy and it is agreed it is in his or her best interests to do so, some landlords will accept an unsigned agreement. If you have any problems, the Housing and Support Alliance has further details on their website: www.housingandsupport.org.uk/tenancy-agreements-for-people-with-learning-disabilities You can also contact the DSA for more information.

A parent's point of view

"Check out what is available very carefully. Put [your relative's] name down for supported living well before you actually want to move out, as it can take a long time, even though it didn't for us. If there is nothing suitable, don't accept that as being final – keep asking and make a nuisance of yourself if you have to!"

Financing housing

Housing benefit

Many people with Down's syndrome who live in their own home receive some form of Housing Benefit to contribute to their rent costs. Housing Benefit is a means tested benefit administered by local authorities and is paid to adults on a low income to help cover their rent. How much you pay will depend on the financial circumstances of your relative, not the family or carer.

Housing Benefit is the only welfare benefit available to pay for rented housing. It is available to tenants over the age of 16 renting their homes in either the private or social rented sectors; it does not provide help with mortgage costs or non-rent related housing costs. The majority of people on a low income or who receive some form of income support or Employment Support Allowance (ESA) will be eligible for Housing Benefit. To find out if your relative is eligible for Housing Benefit, visit the Gov.UK website: www.gov.uk/housing-benefit

Housing Benefit works slightly differently for people in private rented accommodation. You can apply for Local Housing Allowance, a maximum level of Housing Benefit set by the local authority according to the local rental market. Some types of tenancy are exempt from Local Housing Allowance; for example, individuals who rent from a housing association. Call our benefits advisers for more information.

Support for Mortgage Interest

It is possible for some people who are claiming certain benefits to apply for Support for Mortgage Interest (SMI) to contribute to interest payments on a mortgage. If you qualify for Support for Mortgage Interest, your interest payments on a new mortgage payment you take out will be partly subsidised.

The applicant must be claiming the higher rate of the care component of Disability Living Allowance or the daily living component of Personal Independence Payments and one or more of: Income Support, Incapacity Benefit, Employment Support Allowance (Support Group) Severe Disablement Allowance and/or Pensions Credit. See Shelter's website for more details: http://england.shelter.org.uk/get_advice/repossession/mortgage_arrears/support_for_mortgage_interest



Common problems and what you can do about them

Healthy eating, exercise and weight gain

A common issue that families tell us about on our helpline is concern about weight gain when their relative moves out. The temptations of increased freedom around food combined with being in an environment where healthy choice may not be properly supported can lead to some people falling into unhealthy habits.

Sometimes support workers and carers feel that they have to allow your relative to eat unhealthily to avoid restricting freedom of choice. This is not necessarily the case. Your relative may still need to be supported to make decisions about his or her diet, which could include visual reminders about healthy eating and a structured healthy eating programme that supports healthy choice.

People with Down's syndrome tend to be very routine-orientated, so getting healthy living into your relative's daily routine can help establish a healthy lifestyle. Support staff have an important role to play in this regard, building healthy eating and exercise into daily life. If a healthy lifestyle is part of the normal household routine, it will become much easier to follow.

Portion control is good to bear in mind. Support staff can help with portion control by not handing out second helpings on a regular basis, using smaller plates and preparing food in reasonable portion sizes. A dietician can provide further support around portion sizes.

The DSA has a common sense guide to Weight Management and Easy Read resources on healthy eating and exercise available on our website. If your relative is planning to lose weight, has any medical conditions or wants to change their diet or exercise routine, make sure he or she sees the GP first.

Dissatisfaction with support

Families can feel powerless if their relative is receiving insufficient or inadequate support, particularly if he or she lives far away. You should not feel excluded from your relative's care and there are things you can do about it.

In the first instance, arrange a meeting to talk to your relative's support workers or care manager, with the social worker present if possible. Explain your concerns and come up with a plan to tackle them. You may like to show them our Supported Living Guide for Professionals and any other evidence you have to back up your points.

If this approach does not work, contact your relative's social worker and raise your concerns in writing. If you feel your relative's needs are not being met or have not been assessed correctly, you can ask for a full social care reassessment of his or her needs. You can use our social care guides to prepare for any re-assessment.

If the support is funded by the local authority and you can't resolve the issue informally, you can formally complain to your local authority. We strongly suggest that you complain in writing, as this is more likely to lead to a satisfactory response. Your local authority must have a formal complaints procedure on their website. If you are unhappy with the response, you can escalate your complaint to the Local Government Ombudsman:

www.lgo.org.uk/adult-social-care

Staff understanding of Down's syndrome

You may find that some of your relative's support staff may have not had contact with a person with Down's syndrome before. It is of course important for staff to understand that each person with Down's syndrome is an individual. However, they may value specific information about supporting a person with Down's syndrome. The DSA has produced a guide for supported living professionals, which you may wish to share with your relative's care staff or support manager. You or the support provider can download copies via our website. Hard copies are available on request.

Handling high staff turnover

Increasingly families are contacting us to express concerns about high levels of staff turnover. Staff will come and go and this can be quite difficult for your relative to cope with if not handled properly. Preparing your relative adequately beforehand wherever possible can make the situation easier. New staff should also have adequate information

about your relative to ease the transition. Person-centred planning and one-page profiles can help with this.

Unusual behaviour

Sometimes people with Down's syndrome find the change of moving into supported living difficult. Changes in the living environment and routine can make people feel anxious, confused, angry or scared.

Some people with Down's syndrome may feel overwhelmed if encouraged to become too independent, too quickly. This can express itself through behaviour, particularly if your relative cannot communicate emotions verbally.

If you have concerns about your relative's behaviour, or his or her behaviour has changed, try to talk to your relative in the first instance. Visual aids can help if he or she finds it hard to communicate verbally. If this is not working, call a meeting with the social worker and any other professionals involved in your relative's support.

You can work together to identify what is causing the behaviour and how to tackle it. This may involve recording when the behaviour happens to find out what is triggering it. When you have identified the cause, you can arrange a plan of action to prevent the behaviour. Your relative should be involved in this process as much as possible.

Changes in behaviour can be a sign that someone is unwell or in pain and certain health problems can directly cause behavioural changes (e.g. urinary tract infections, underactive thyroid, seizures, Vitamin B12 deficiency). Your relative's GP can help rule out any medical causes. Make sure that support staff are aware of the DSA Adult Health Book and materials available on health issues related to Down's syndrome on our website.

If your relative appears to be showing signs of tiredness, low mood, loss of interest in activities previously enjoyed, etc., your relative may be exhibiting signs of depression.

The changes of moving into supported living can lead to some people experiencing anxiety or depression; however, depression is a complex condition which can be affected by a number of factors. If you are concerned that your relative is experiencing depression, make sure he or she sees a GP. The DSA has general information about depression available to download on our website.

If you are really worried about your relative's behaviour, contact your local community learning disability team and ask to see a psychologist with an understanding of learning disability. You can also call the DSA helpline for support.

Problems with housemates

Just like any group of people living in one place, there can be arguments or disagreements in your relative's household. However, sometimes these problems can become more serious.

No one should feel harassed, threatened or bullied in their own home. Families are sometimes worried about raising concerns as they feel they may not be listened to. It can be helpful to write down exactly what has happened, when it happened and what your relative has told you. You can then share this information with the social worker and support team. If your relative has a circle of support, you can raise your concerns with them and discuss the best way to tackle the issue. This can help ensure that the concern is raised by a number of people interested in your relative's welfare, rather than just one person.

If your relative tells you something that indicates abuse or if you feel he or she may be at risk, raise your concerns with the social care safeguarding team immediately.

Dementia

Families are sometimes concerned about dementia. Whilst people with Down's syndrome generally develop dementia at a younger age than in the general population, it is not inevitable that your relative will develop dementia.

Dementia is the name given to a collection of diseases, such as Alzheimer's disease, that have a characteristic pattern of symptoms and generally occur in later life. The main characteristics of dementia include deterioration in the person's memory (usually short term memory) and loss of other abilities, including the ability to find one's way around, to communicate through language and to undertake everyday tasks such as getting dressed. Dementia due to Alzheimer's disease is a steadily progressive disorder with evidence of decline over time.

However, there are many other treatable medical conditions and psychological problems that can appear to be dementia or Alzheimer's disease. These conditions should be checked for before a diagnosis is made. Possible health conditions include: poor hearing, poor vision, hypothyroidism, brain tumours, vitamin B-12 deficiency and depression. Any one, or a combination, of these conditions may look like dementia. Since these are treatable, it is vitally important to have a full medical assessment at an early stage to rule them out.

If you are worried that your relative may be showing symptoms of dementia or Alzheimer's disease, speak to a GP. The DSA has downloadable booklets on 'Ageing and its consequences' and 'Alzheimer's disease' with more information.

Remember – supported living is a journey!

It can feel a little overwhelming when you start thinking about supported living. It might be helpful to think of moving into supported living as a journey. Just as every person with Down's syndrome and their family is different, so is everyone's journey towards supported living and there may be bumps along the road. That doesn't mean your relative won't get there in the end.

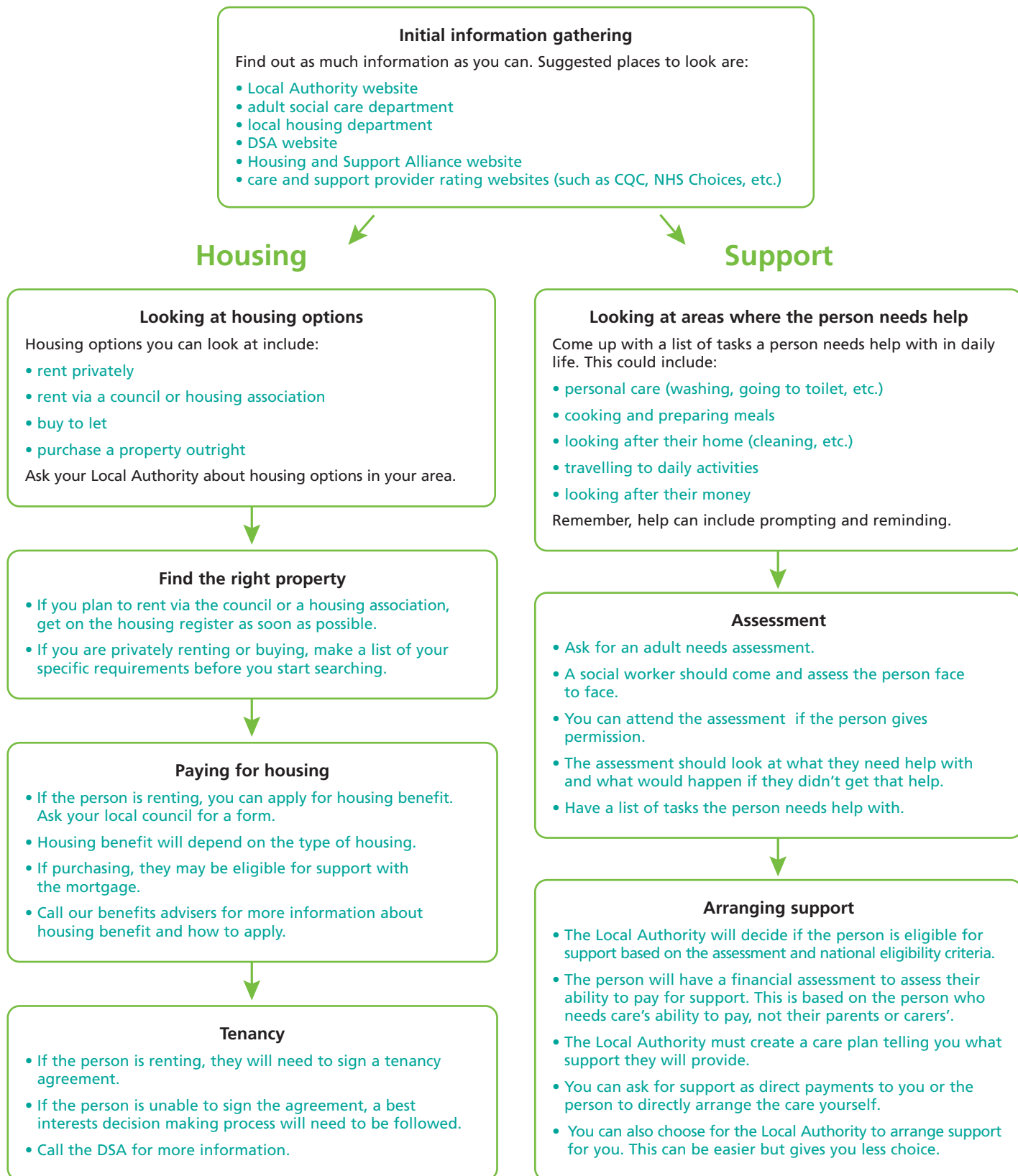
Don't panic if you experience setbacks or your relative does not settle into his or her new home straight away. The road to independence is not a straight one and there may be times when your relative needs more support or experiences a problem. The important thing is to ensure that you and your relative are getting enough support.

If you would like more information about supported living, or you just need some advice, the DSA Information Team is here to help you. You can contact the Information Team on 0333 1212 300 or email info@downs-syndrome.org.uk One of our Information Officers will be happy to talk to you and offer support and advice.



Supported living flowchart

This flowchart explains the supported living planning process



Further resources

Down's Syndrome Association Publications

Supported Living Series

Supported living videos highlighting the stories of adults with Down's syndrome in supported living are available on our website.

Supported Living Series: Easy Read

A series of 'Easy Read' booklets for people with Down's syndrome on topics around supported living.

Supported Living Series: Making Supported Living Work for People with Down's Syndrome – Information for Support Staff

Information for support staff on supporting people with Down's syndrome who live in their own home.

Visit the DSA website for further resources and information on supported living.

Mental Capacity Factsheet

This factsheet has information on decision making, mental capacity and the law for families and carers. You can download the factsheet from the DSA website.

Health Series

A series of 14 booklets on a range of health and medical conditions written for parents and carers. The Health Series is available for download on the DSA website. Print copies can be ordered on request.

Common Sense Guide to Weight Management

A common sense guide with top tips on maintaining a healthy weight and lifestyle for people with Down's syndrome. You can download the guide from the DSA website.

Benefits Series

A series of factsheets on benefits and financial support. You can find up to date benefits information on the DSA website.

Other organisations

Foundation for People with Learning Disabilities

Thinking Ahead: A Planning Guide for Families
www.learningdisabilities.org.uk

Housing and Support Alliance

Information about housing, support and your rights:
www.housingandsupport.org.uk

Skills for Care

Information on hiring a personal assistant, including information in Easy Read:
www.paskills.org.uk

The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome.

We also work to champion the rights of people with Down's syndrome, by campaigning for change and challenging discrimination.

A wide range of Down's Syndrome Association publications can be downloaded free of charge from our website.

Contact us

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