DSUK
Down Syndrome UK

Future Pathways

Part 3: Housing and Support



Introduction

For many parents, "where will my son or daughter live when I can't support them?" is the biggest question of all.

The honest answer is that there is no single right option. Many adults with Down syndrome live with family well into adulthood, and that can work well. Others want their own front door, with friends, in a place of their choosing. Both are valid.

What matters is that housing is planned, not left until a crisis. This part explains the main options, how they are funded and what to ask. Housing and care are two separate things that need to work together.



Important: this guide covers England only
This guide reflects housing, social care and benefits law and practice in **England only**. Housing law, regulation and funding are different in **Wales, Scotland and Northern Ireland**. Separate guides for those nations are being produced. If you live outside England, please don't rely on this guide.

Some examples are real families, referred to by an initial. Others are made up to show how things work, and are marked "illustrative". Figures won't match any individual's situation.

Please read: this is not financial or legal advice. This guide is general information, shared in good faith by parents and Down Syndrome UK from our own experience and research. Rules and figures change, and every family's situation is different. Always check with the right organisation, and take professional advice, before making decisions.

Key terms

Term	Plain English meaning
Tenancy	A legal agreement giving someone the right to live in a home, with rights such as security and protection from unfair eviction.
Licence / occupancy agreement	A weaker form of agreement: the person may live in a home but with fewer legal protections than a tenant.
Landlord	The organisation or person who owns or manages the home (often a housing association).
Care / support provider	The organisation that provides the support. This may or may not be the landlord.
Supported living	Someone has their own home (usually with a tenancy) and receives support separately.
Shared Lives	A person lives with, or regularly stays with, an approved carer and their family.
Registered care home	A home registered to provide accommodation together with personal care.
Housing Benefit	Money that helps pay rent.
Service charge	A charge for services in the building, such as repairs to shared areas.
Local Housing Allowance (LHA)	The most Universal Credit or Housing Benefit will pay towards private rent in your area.
Joint tenancy	One tenancy shared by two or more people, each with their own share of the rent.
Housing register	The council's waiting list for council and housing association homes.
Discretionary Housing Payment	Extra help from the council when benefits don't cover the rent.



Housing and the Care Act

Under the Care Act, **suitability of accommodation** is one of the wellbeing factors the council must consider (see Part 1). If the council decides your young person's needs can only be met in a particular type of accommodation, such as supported living, Shared Lives or a care home, this should be recorded in the Care and Support Plan. It also matters if they move to another area: under section 39 of the Care Act, the council that arranged the move usually stays responsible.

Housing is about much more than a roof. It is about:

- **who** the person lives with, or whether they want to live alone
- **where**: near family, friends, work, college, shops and transport
- **how much support** they need and when
- **control**: how much say they have in daily life
- **security**: whether it is a long-term home they can rely on

Something that's easy to miss: the best time to start talking about housing is long before it is needed. Many people start in the transition years (see Part 1). Waiting lists, planning and matching take time.

The main options

Option	What it is	Good to know
Living with family	Support from PAs, day opportunities and short breaks	Can work well long term, but needs a plan for the future
Supported living	Own tenancy, with support from a separate provider	From a few hours a week to 24/7
Shared Lives	Lives with an approved carer and their family	Long-term, short breaks or day support
Registered care home	Accommodation and care together	Fewer rights than a tenant. Different charging rules
Renting a home, with PAs or an agency	Private or social rented home, with support through a personal budget	Help with rent is capped by the LHA rate in private renting
A family-bought home	Family buys; young person lives there, as owner, beneficiary or tenant	Big financial, tax and legal decisions
Shared ownership	Young person buys a share of a home	Affects benefits and capital. Take advice
Living independently, with floating support	Their own rented or owned home, with occasional visits from support staff	Works well for people with lower support needs and a strong network nearby

1. Living with family (with support)

Many adults with Down syndrome remain with parents. Support may come from the council, a Personal Assistant, a care agency, day opportunities or short breaks. This can be a positive, lasting choice. It also needs a **plan for the future**, including what happens if family can no longer provide care (see "Emergency and long-term planning" in Part 4).

Council tax at home. At 18 your young person counts as an adult for council tax, unless they're "disregarded" as severely mentally impaired, which many people with Down syndrome are:

Who lives at home	Adults counted	Council tax
Single parent and young person (disregarded)	1	**25% discount**
Two parents and young person (disregarded)	2	Full bill
Two parents and young person, with one parent also disregarded as a carer	1	**25% discount**
Young person living on their own	0	**No council tax**

- **Carer disregard:** once your son or daughter is 18, a parent caring for them 35+ hours a week can also be disregarded, if they get a qualifying benefit such as the enhanced rate of PIP daily living. Getting Carer's Allowance doesn't reduce council tax on its own.
- **Disabled Band Reduction:** if your home has a room, bathroom or space your young person needs because of their disability, the bill may drop by one band.
- **Apply to your council.** The severe mental impairment disregard usually needs a doctor's confirmation and a qualifying benefit.

Paying board, not rent.

- Your young person can pay you **board**: a contribution towards food, bills and household costs. It isn't rent.
- UC doesn't pay housing costs for someone living with their parents, so board comes from their own income, such as UC and PIP. It comes out of their protected Minimum Income Guarantee.
- Agree a fair amount based on what it actually costs you, write it down, and review it each year.
- For parents, board isn't usually taxable income, and UC ignores it.

See Sally's example in Part 2 for a full month's money for a young person living at home.

Example (illustrative): Sally plans ahead. Sally, 20, lives with her parents and goes to a day service three days a week. Her parents want to plan for the long term. They: recorded Sally's housing hopes in her Care and Support Plan: she wants her own flat near her sister - put her name on the housing register and asked about supported living, because waits can be long - started a **future plan**, including an emergency plan, a letter of wishes and legal advice (Part 4).
What made the difference: starting early, and writing Sally's own wishes into the plan.

2. Own tenancy, with support: supported living

In **supported living**, the person has their own home, such as a flat or a room in a shared house, and a **separate** support provider helps them with the things they need.

- The person usually holds a **tenancy** and has the legal rights of a tenant.
- **Housing is provided** by a landlord (often a housing association).
- **Support is provided** by a care provider, funded through the personal budget (Part 2).
- Support can range from a few hours a week to 24-hour cover, often shared among housemates, with some 1:1 hours each.

Why separate matters.
Good practice is for the landlord and support provider to be different organisations, so your young person can change support without losing their home. **The risk if they're one and the same**: if the support isn't working, changing provider could mean losing the home. And if the home depends on accepting that provider's care, the Care Quality Commission (CQC) may treat it as a care home. Some charities and housing associations do provide both, which isn't banned, but the tenancy must not depend on accepting their care.

Ask: "If we're unhappy with the support, can we change provider and stay in the home?"

Questions to look at:
- Who holds the tenancy, and what does it say?
- How are housemates chosen, and what happens if people do not get on, or someone moves out?
- How much control does the person have over daily life: meals, visitors, routines?

Sharing staff can make support more affordable, but costs vary widely between areas and providers.

3. Shared Lives

In **Shared Lives**, an adult is matched with an approved Shared Lives carer, who shares their home and family life with the person. It can be long-term, short breaks or day support.

- Shared Lives is run by **registered schemes**, and in England schemes that provide personal care are **regulated by the Care Quality Commission (CQC)**.
- Carers are **assessed, approved, trained and monitored** by the scheme.
- Carers are usually **self-employed** and receive a payment.
- **Matching** is central: shared interests, personality and expectations are considered.
- The person is usually in an **occupancy agreement** with the carer rather than a tenancy. Arrangements vary, so ask what protections apply.
- Many families find this a **warm, family-style** option, especially for people who want companionship and a home atmosphere without living alone.

Example (illustrative): Grace. Grace, 30, lives with a Shared Lives carer and her family in a town she knows, and goes to a drama group and a work placement. Her home and support are largely funded through the council's personal budget, which pays the scheme and carer. Grace pays a contribution based on her financial assessment, with MIG and DRE protections, and pays her everyday costs from her own money.
What to ask: what her rights are under her agreement, what happens if the carer is ill or moves, and how the match is reviewed.

4. Registered care homes

A **registered care home** provides accommodation and personal care together, from the same organisation. These are a minority choice for younger adults with Down syndrome today, but may be right for some, particularly with high or complex needs.

	Care home	Supported living
Home	A room in a registered care home	Their own home, with a tenancy
Who provides it	One organisation provides the home and the care	Landlord and support provider should be separate
Rights	No tenancy, fewer rights	A tenant's rights
Help with rent	None: it's all part of the care fee	Housing Benefit or UC
Money they keep each week	Personal Expenses Allowance: £31.80 (2026/27)	MIG: £172.10 if under 25
If they own a home	Can count towards fees after 12 weeks	Counts if they've moved out of it

Ask whether other options have been considered. The Care Act expects councils to consider the person's wishes and choice.

5. Renting a home, with support

Your young person can rent a private or social home, with support from PAs or a care agency paid for by their personal budget (Part 2). See "Help with rent" and "Applying for council or housing association housing" below.



6. Buying a home for your young person

	Through a trust	You or your company as landlord	Shared ownership
Who owns it?	Trustees (for example, parents or siblings)	You, or your company	Your young person owns a share. A housing association owns the rest
Who pays for it?	The **family or trust**: buys it and pays the running costs	**The family** buys it. Your young person pays rent	**Your young person** buys a share (often with family help) and pays rent on the rest
Does UC help?	No. They usually live rent-free	Yes, with the rent, up to the LHA rate	Yes, with the rent part. A Support for Mortgage Interest loan can help with the mortgage
Stamp duty on £300,000	Usually £20,000	£20,000 (assuming a second home if bought by an individual)	Often nothing on a 25% share: it's usually only charged on the share
Counts as their savings?	Usually not, if discretionary	No	Their share doesn't, while they live there
What happens later?	Trustees carry on after you die. The trust says what happens next	Passes under your will, or the company carries on	Their share is theirs: they need a will (or a statutory will)
Complexity	High	High	Medium: specialist help available, for example from My Safe Home

Buying a whole home in your young person's name is possible, but it depends heavily on their capacity, the lender and your family's situation, so take specialist advice first:

- **Mortgages:** lenders rarely lend to someone on benefits alone. Some families use a "joint borrower, sole proprietor" mortgage, where a parent's income helps with the mortgage but only the young person owns the home (which can avoid the higher stamp duty rate for a second home), or a guarantor mortgage. Either way, the parent is legally responsible for the mortgage. Many families buy outright instead.

- **Capacity:** your young person needs capacity to buy and own the home, or a deputy with Court of Protection approval.

- **Savings:** the home isn't counted as savings while they live there, but it does count if they move out. Money you give them counts as their savings until it's spent on the home.

- **What happens when they die:** if they haven't made a will, the home passes under the intestacy rules, usually to their parents or siblings. If they can't make a will themselves, the Court of Protection can authorise a statutory will.

Talk to a specialist mortgage broker and a STEP solicitor before buying.

Through a trust: trustees, such as parents, siblings or a professional, own the home and keep managing it after you've gone. A discretionary or disabled person's trust usually isn't counted as your young person's savings. UC usually won't pay rent to a trust they benefit from, so most live rent-free, **and the trust or family pays the property costs**, such as any mortgage, insurance and repairs. Any rent charged would have to come from your young person's own income. Trusts usually pay higher stamp duty, have complex tax rules, and cost money to set up and run. You can set one up now, or leave the home to a trust in your will.

Renting to your young person: the numbers (illustrative).
A £250,000 home with a £168,000 interest-only mortgage, £850 a month rent (the UC amount) and £1,000 a year other costs. Company mortgages usually cost more, so that column uses 6%:

Per year	You own it (higher-rate, 5%)	You own it (basic-rate, 5%)	Your company owns it (6%)
Rent	£10,200	£10,200	£10,200
Mortgage interest	£8,400	£8,400	£10,080
Profit HMRC taxes	£9,200 (interest not deducted)	£9,200	−£880 (interest deducted, so a loss)
Tax before credit	£3,680 (40%)	£1,840 (20%)	£0
Less 20% credit on mortgage interest	−£1,680	−£1,680	n/a
Tax to pay	**£2,000**	**£160**	**£0**
Cash left after tax	**−£1,200**	**£640**	**−£880**

Only the interest part of a mortgage can ever be deducted, never the capital repayments.
The LHA rate often decides whether buying makes financial sense at all.

Before you buy, ask:
- **Who will own it**, and what will that mean for stamp duty, tax and inheritance?
- **Will UC or Housing Benefit cover the rent?** Check your area's LHA rate first.
- **Is it a genuine commercial tenancy**, with a market rent and a proper agreement? DWP will check.
- **Can your young person sign the tenancy**, or will someone need legal authority? (Part 4)
- **What happens to the property when you die**? (Your will and any trust)
- **Are you ready for a landlord's legal duties**, such as gas safety, electrical checks and deposit protection?

Shared ownership: some adults with Down syndrome buy a share of a home, usually a new build, and pay rent on the rest to a housing association. It gives security of tenure, a choice of where and who with (including an extra bedroom without the "bedroom tax"), and the freedom to change care provider without losing the home. The homeowner is responsible for all repairs and maintenance, even though they only own a share.

(mysafehome.info, T: 02476 402211, E: enquiries@mysafehome.info)

My Safe Home, set up by David Abbey, **arranges specialist mortgages for people with disabilities** and has helped more than 1,600 disabled people on benefits become homeowners since 1999. Their key criteria are: aged 18 or over; getting PIP daily living (or the middle or high rate of DLA care);getting UC with LCWRA (or in the ESA support group); at least about £13,000 for the deposit and buying costs; and able to contribute about £130 a month from disability benefits towards housing costs. The maximum mortgage is £100,000. Limited capacity may need an LPA or deputyship.

A real example (My Safe Home, October 2025): a £300,000 home, buying a 25% share

Buying the share	
25% share	£75,000
Specialist mortgage	£71,250
Deposit	£3,750
Fees	£8,000
Upfront cost (from savings, a trust or family)	**about £11,750**

Each month	
Rent on the 75% owned by the housing association	£387
Service charge	£100
Paid by UC or Housing Benefit	**£487**
Interest-only mortgage	£323
Covered by a Support for Mortgage Interest (SMI) loan	£217
Topped up by the homeowner from their benefits	£106

The interest-only mortgage and the SMI loan are repaid from the sale of the homeowner's share when the home is sold, and any shortfall on the SMI loan is written off. ***Check current mortgage rates and deposits with My Safe Home.***

Get specialist advice *from a STEP solicitor and an accountant, ideally together, before buying a property or putting a home in a person's name.*

7. Living independently, with floating support

Some adults with Down syndrome live in their own rented or owned home, with **floating support**: occasional visits from support staff rather than staff on site.

They manage most of daily life themselves, with help where needed:

- **Budgeting:** managing rent, bills and food shopping
- **Life skills:** cooking, cleaning and getting around the community
- **Technology:** reminder apps, easy-read timetables and smart devices can support independence

This can work well for people with lower support needs, good daily living skills and a strong support network nearby.

Tip: these options aren't either/or. Many adults move between them at different stages of life. Planning early, and trying small steps towards independence, makes transitions much smoother.

8. Other options

- **Extra care housing** and **housing with support** schemes (some are open to younger adults).
- **Co-housing or family-led housing** projects, where families come together to create a home.

Right to choose

The Care Act is built around **choice and control**.

- The person's **wishes, feelings and preferences** should be central.
- There is no automatic right to any one type of home, and the council will consider cost. But the council should not simply place someone in whatever is cheapest or available.
- For **registered care homes, Shared Lives and supported living**, the person has a legal right to choose a particular home, as long as it suits their assessed needs, has a place, the provider accepts the council's terms, and it costs no more than the personal budget allows. If it costs more, a family member or friend may be able to pay a "top-up".
- If you feel a decision restricts choice unfairly, **ask for reasons in writing** and use the review and complaints routes described in Part 1.



Understanding tenancy agreements

When your young person moves into their own place, whether supported living, shared housing or living independently, they'll usually sign an agreement that sets out their rights and responsibilities. The right agreement gives them **security** (protection from being unfairly asked to leave), **legal rights** (to challenge problems, repairs or unfair treatment) and control over who comes into their home and how they live.

Type of agreement	What it means	Rights and protections	Choice and control
Excluded licence	Often used in Shared Lives, or when living with a resident landlord. Not a full tenancy	Few legal protections. The landlord doesn't need a court order to end it, and only limited notice	Limited control over their home
Licence	Permission to live in a property, but not the same security as a tenancy	Some rights, but easier to end, with shorter notice	Some say in how they live, but less than a tenancy
Assured periodic tenancy (APT)	Under the **Renters' Rights Act**, assured shorthold tenancies (ASTs) became assured periodic tenancies on 1 May 2026 for private landlords. For housing associations, the change comes in October 2027. The most common type in supported living and rented homes	Strong protections. "No-fault" evictions have ended, so a landlord can only end the tenancy on specific legal grounds, through the proper process	Full rights as a tenant: choice over who visits, how they decorate, and more
Non-assured tenancy	Used in some supported living settings	Fewer protections than an assured tenancy, but more than a licence. If you're offered one, ask why it isn't an assured tenancy	Some control, but may be shared with the support provider

Good to know: the Renters' Rights Act includes two new grounds for ending a tenancy in **supported accommodation:** if the home no longer meets the person's needs, or if they unreasonably refuse to engage with the support. Ask the landlord how these would be used.

Tip: ask your council, housing provider or an independent advocate to check which agreement is being offered, and whether it's the most secure option for your young person.

Housing costs: how they are paid

In supported living, the money usually has **three separate strands**:

Strand	What it pays for	Typically funded by
Rent	The home itself	Housing Benefit, possibly with the person's own income
Service charge	Services such as communal repairs and cleaning	Partly Housing Benefit, partly the person. Housing Benefit can cover communal services such as cleaning shared areas and some housing management, but not personal care, food, or energy and water for the person's own use
Care and support	Staff and support hours	Personal budget (council, plus the person's contribution after the financial assessment)

On top of this, the person pays for **everyday living costs**: food, bills, travel, social activities and clothing. This is what the Minimum Income Guarantee and DRE help protect (Part 2).

Rent in supported living. In most supported living, rent goes through **Housing Benefit**, not Universal Credit. You claim it from the council, and it's usually paid straight to the landlord. It's a national benefit that the council runs, not the council's own money. It can cover rent and some service charges, and usually isn't capped at the LHA rate. This applies where the landlord is a housing association, charity or voluntary organisation and care, support or supervision is provided (often called "exempt" or "specified" accommodation). Where the landlord is a private individual or a family company, rent usually goes through UC instead, capped at the LHA rate. Check with the provider.

Monthly (illustrative, single, under 25)	
UC standard allowance	£338.58
UC health element (LCWRA, existing claim)	£429.80
UC housing element	£0 (rent is paid by Housing Benefit instead)
Total UC paid to the young person	**£768.38**
Housing Benefit, paid by the council, usually straight to the landlord	About £823 a month (£759.44 every 4 weeks) for a room in a shared house

The rent is a real example from a supported living house in Warwickshire in 2025.
Rents vary a lot by area and provider.

Help with rent: Local Housing Allowance (LHA)

If your young person rents privately, UC helps with rent up to the **LHA rate** for the area and their household.

- **The under-35 rule:** single people under 35 are usually only allowed the rate for a room in a shared house. **Getting the PIP daily living component exempts them**, so they can get the one-bedroom rate.
- **An extra bedroom for an overnight carer:** if they need care overnight, their rate goes up to allow a carer's bedroom.
- **If there's a shortfall**, ask the council about a **Discretionary Housing Payment**.

Monthly LHA rate, 2026/27	1 bedroom	2 bedrooms (with carer's room)
Leamington Spa	£700	£850
Kensington and Chelsea (Central London area)	£1,439.97	£1,793.98
Grimsby	£395	£480

Look up your own area with the LHA Direct tool at **lha-direct.voa.gov.uk**: enter your postcode.
The tool shows weekly rates; to get monthly, × 52 ÷ 12.

Real example: renting with 24/7 support. One young man rents a 2-bed home for £1,250 a month. Because he needs 24/7 support, his LHA rate rose from £700 to £850 to allow a carer's bedroom. That still leaves a £400 a month shortfall, which he pays himself.

Sharing with a house buddy

With a **joint tenancy**, UC splits the rent and each person claims for their own share, up to their own LHA rate.

Example (illustrative): Finley in Leamington Spa

Monthly	Renting alone	Renting alone, needs 24/7	Sharing	Sharing, needs 24/7
Home	2-bed, on his own	2-bed, on his own (staff sleep in)	2-bed, with a buddy	3-bed, with a buddy (room for sleep-in staff)
Total rent	£1,250	£1,250	£1,250	£1,500
Finley's share	£1,250	£1,250	£625	£750
Most UC will pay	£700	£850	£700	£850
UC housing help	£700	£850	£625	£750
Shortfall Finley pays	**£550**	**£400**	**£0**	**£0**

- What the buddy gets depends on them: up to £700 if they also get PIP daily living, or the shared accommodation rate if not (about £411 a month in Leamington), which would leave them around £214 a month short on a £625 share.
- **Council tax:** none at all if both housemates qualify as severely mentally impaired.
- If both need support, they can also **share some staff hours**.

Applying for council or housing association housing

- **Join the housing register.** Your young person can usually apply in their own name from 18. Some councils accept applications from 16.
- **Each council has its own rules.** Most expect a local connection, and many use a points or banding system.
- **Ask for priority** on medical or welfare grounds because of their disability. Send evidence from the GP, social worker or occupational therapist.
- **Waits can be long,** sometimes years. Ask whether time on the list counts, and if so, apply early.
- **Many councils share a register** with local housing associations, and some keep a separate list for adapted homes.
- **Rent:** UC usually covers the actual rent for social housing, including an extra bedroom if they need an overnight carer.
- **Signing the tenancy:** if they can't understand it, someone may need legal authority (Part 4).
- **Mention housing plans** in the Care and Support Plan too, so social care and housing teams work together.



Real families' stories

Shared with permission. Names have been reduced to initials.

C: finding the right home

- C's mum used her EHCP review and a meeting with social workers to make clear that C wanted to live Independently.
- The provider spent two hours getting to know C. They visited several homes and chose a modern shared house 20 minutes from family.
- C met staff and housemates on Zoom before moving in, at 23, after residential college.
- **Support:** 31.5 hours of shared support and 24.5 hours of 1:1 a week, plus a full-time supported internship.
- **Money:** rent is covered by Housing Benefit. C contributes £212 a month towards her care from her Universal Credit.

"My husband asked me several times: are we doing the right thing? And I said, categorically, absolutely." **— C's mum**

R: creating a home from scratch

- A relative of another family bought a four-bedroom house: three bedrooms for the young people, one for sleep-in staff.
- It's kept homely, not institutional: the only signs of support are a menu plan and noticeboards.
- The families emailed more than 70 CQC-registered providers, interviewed 20 on Zoom and visited 3. They chose a small, values-led company focused on empowerment rather than "care".
- **Support:** 28 hours of 1:1 a week, plus shared hours and sleep-in staff.
- **Money:** rent is covered by Universal Credit. Housemates share the bills, with a joint household account and a shared car.
- R's family has also experienced a housemate moving out, so plan for what happens if that happens.

"R would've been happy to come home, but one day we won't be here. We want her settled, with all the bumps ironed out while we're still around to help." **— R's mum**

F: learning as you go

- F moved in at 24, after four years at residential college.
- A structured week with volunteering and activities, and 1:1 support with shopping, banking, meal planning and appointments.
- Money: rent covered by Housing Benefit, care commissioned by the council, day-to-day income from Universal Credit.
- Being involved in choosing his house and routines gave him ownership and excitement.

"There was no template. We had to learn as we went. Supported living isn't about getting it perfect from the start, it's about building something that grows with your child." **— F's mum**

When it didn't work

One young man moved into supported living but left after three months. The provider couldn't get him to his activities because of staffing levels and distance, and the relationship between the provider and his family broke down quickly. He said clearly that he didn't want to go back. His family then bought a home through their company, which he rents, with a team of PAs funded by his direct payment providing 24/7 support.

What they learned: set clear expectations, plan the transition together, and make sure everyone shares an understanding of mental capacity and risk.

What these families tell us

- Start early, and use EHCP reviews to put independent living on the agenda.
- Involve your young person in visits, choices and meeting housemates.
- Be prepared to search hard: one family contacted 70 providers.
- Choose a provider whose values match yours.
- Stay involved, and build a good relationship with the staff team.
- It doesn't have to be perfect from day one. It can grow and change.
- Plan for the long term, including what happens if a housemate moves out.



What different adult lives can look like

- **His own home, with a PA team**: a home his family bought, with 24/7 support from PAs paid by his direct payment.
- **Shared supported living (C and F)**: a shared house with 24/7 staff, 1:1 hours, and work, volunteering or an internship.
- **A home families created (R)**: three friends share a family-bought house, with a provider the families chose.
- **Renting, with full-time support (Josh, illustrative)**: a private rented home; UC helps with rent, and his care is paid for by his personal budget (see Part 2).
- **Living at home (Sally, illustrative)**: with her parents, at a day service, paying board and building skills for later.
- **Shared Lives (Grace, illustrative)**: living with a carer's family in a town she knows.

There's no single right answer. The best home is the one built around your young person.

The process: what to expect

1. **Talk about it at the assessment and the review**. Make sure your young person's hopes about housing are written into the Care and Support Plan.

2. **Ask about options and waiting lists**. This includes the council's housing team and local housing associations, which are different from the social care team.

3. **Visits and trial stays.** Visit at different times of day. Meet housemates and staff.

4. **Matching.** For supported living and Shared Lives, how well people match matters enormously.

5. **Agreements.** Tenancy, Shared Lives agreement or care home contract. Read carefully and ask for Easy Read copies.

6. **Moving in and review**. There should be a review soon after the move, then regular reviews.

Capacity and signing agreements

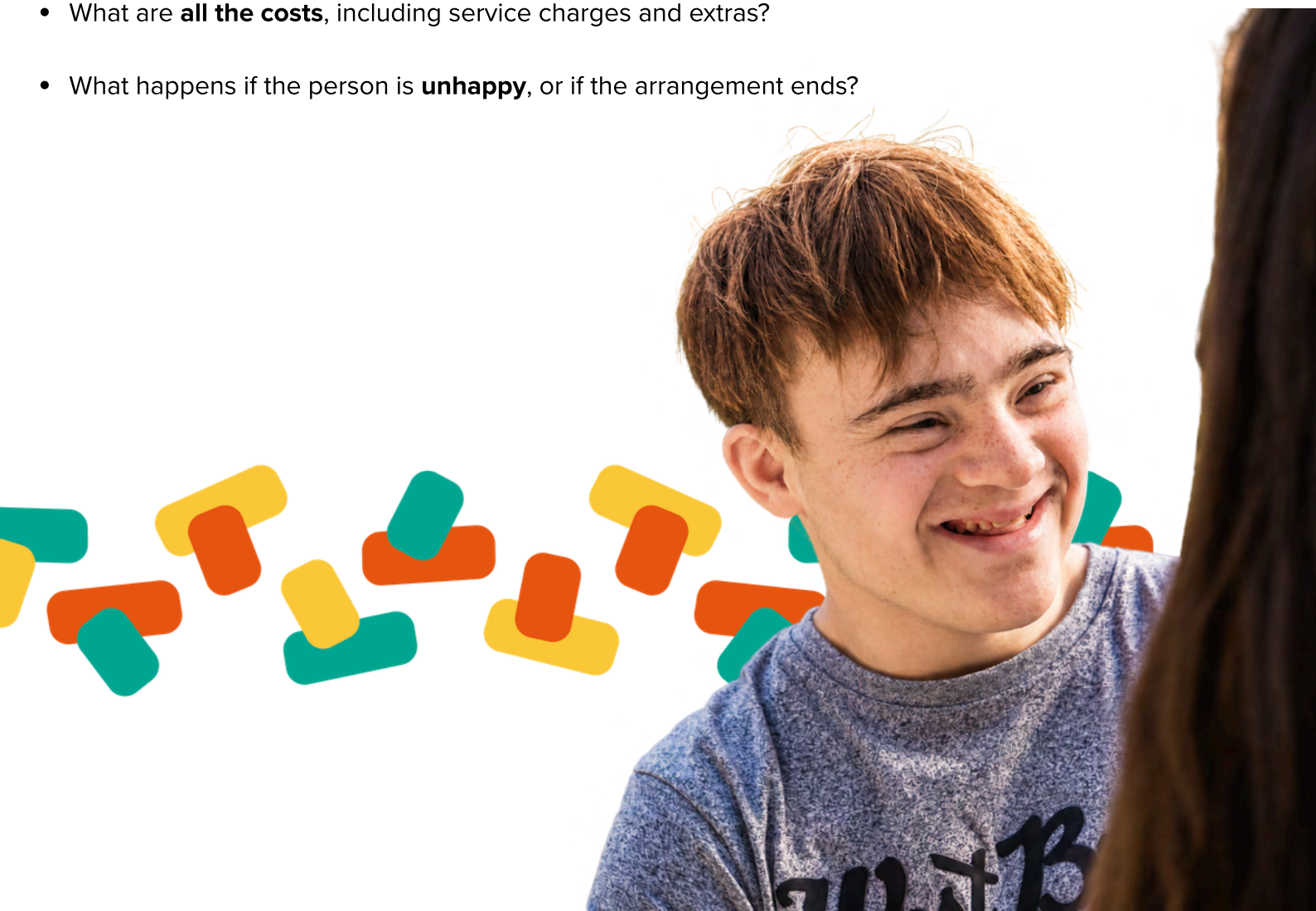
To sign a tenancy, a person must have the **mental capacity** to understand it, with support. A relative cannot automatically sign on their behalf. If they can't sign, someone needs legal authority: a property and financial affairs **attorney** (if they made an LPA), a **deputy** with authority to sign tenancies, or a one-off Court of Protection order (see Part 4). Ask early, as it can delay a move by months.

Timescales

Housing can take **months or years**. Do not wait until there is a crisis.

Choosing a provider: questions to ask

- Is the **landlord** separate from the **support provider? If we're unhappy with the support, can we change provider and stay in the home?**
- What is the provider's **CQC rating**, and can we see recent inspection reports? (CQC registers and inspects providers that give **personal care**, including supported living agencies and Shared Lives schemes. It doesn't regulate landlords or the housing itself.)
- How much **staff turnover** is there, and are staff consistent?
- How do they **involve the person** in decisions: menus, rotas, house meetings, choosing staff?
- What are the **house rules**, and what choice does the person have about visitors, relationships and routines?
- How do they support **health needs** (annual health checks, appointments, thyroid, hearing and vision, sleep apnoea)?
- What is the approach to **ageing and dementia**, since people with Down syndrome are at higher risk? Can the person stay in their home if needs increase?
- How do they keep people s**afe from exploitation** while supporting independence?
- What are **all the costs**, including service charges and extras?
- What happens if the person is **unhappy**, or if the arrangement ends?



Compiled by Bev Couzens.

Questions for a supported living provider

General information

1. What is the age range and profile of residents?
2. How do you tailor support to meet individual needs?
3. What is the staff-to-resident ratio?
4. Are staff trained in working with young people with learning disabilities?

Care and support

1. How do you develop and review care plans?
2. How do you support independence and daily living skills?
3. How do you handle medical needs, including managing medication?
4. What therapies or specialist support are available, such as speech and language therapy or occupational therapy?
5. How do you communicate with families and involve them in care decisions?
6. How are one-to-one hours assessed and allocated?

Education, employment and activities

1. Do you support residents to access education or employment, including transport to and from college?
2. What activities and social opportunities do you provide?
3. What are the interests of the other residents?
4. How do you support residents to develop life skills, such as cooking, budgeting and travel training?
5. Do you offer any structured programmes or personal development opportunities?
6. Will staff take residents out in their own car, such as a Motability car, for activities?

Safety and wellbeing

1. How do you keep residents safe, both inside and outside the home?
2. How do you handle challenging behaviour and conflicts?
3. What measures are in place to protect against abuse and neglect?
4. How do you support residents' mental and emotional wellbeing?

Accommodation and daily life

1. What are the living arrangements like, such as private rooms and shared spaces?
2. Can residents personalise their rooms?
3. What are the house rules and expectations?
4. How do you support dietary needs and preferences, particularly healthy eating and weight management?
5. What is the policy on visitors, and overnight stays with family?

Transition and future planning

1. How do you support new residents to settle in?
2. What is the process for moving towards greater independence in the future?
3. What happens if a resident's needs change over time?

Costs and funding

1. How is the support funded, for example by the local authority or privately?
2. What costs are covered, and what extra expenses might there be?

Feedback and reviews

1. How do you measure and monitor the quality of care?
2. Can we speak to current residents and their families, and to former housemates and their families, about their experiences?
3. What happens if we have concerns or complaints?

Checklist: housing planning

- [ ] Have we written the person's housing hopes into their plan?
- [ ] Have we asked the council about options in our area, including supported living and Shared Lives?
- [ ] Have we joined the **housing register**, and asked for medical or welfare priority?
- [ ] Do we understand how **housing costs and benefits** will work, including our area's **LHA rate**?
- [ ] If sharing, is it a proper **joint tenancy**?
- [ ] Are the landlord and support provider separate? Can we change provider and stay?
- [ ] Have we visited more than one option?
- [ ] Have we asked about the **tenancy or agreement** and what protections it gives?
- [ ] Have we thought about **capacity** and signing agreements?
- [ ] Have we taken advice before buying a property or changing ownership?
- [ ] If living at home, have we applied for the council tax disregard and agreed board?
- [ ] Do we have an **emergency plan**?

Where to find out more

- **DSUK's supported living video**: watch on YouTube
- **My Safe Home** (mysafehome.info), for shared ownership and specialist mortgages. T: 02476 402211, E: enquiries@mysafehome.info. Free initial guidance.
- **Learning Disability England's housing guide**, developed with Housing LIN and ACE Anglia: accessible information on housing options and rights
- **Mencap's Housing Law Toolkit**: tenants' rights, eviction, accessible housing grants and legal protections for disabled tenants
- **Citizens Advice:** free advice on housing, tenancies and benefits
- **Equality Advisory and Support Service (EASS)**: free guidance on equality and human rights in housing. T: 0808 800 0082.
- **LHA Direct** (lha-direct.voa.gov.uk), for Local Housing Allowance rates

Myth-busters

"Supported living means living in an institution."
Supported living means having your own home with a tenancy and separate support.

"If he moves out, we lose the right to be involved."
Families can remain involved. Many providers value this. It should be agreed with the person.

"UC will pay the full rent."
Not in private renting. UC pays up to the LHA rate for your area, so check it before choosing a home. In most supported living, Housing Benefit usually covers the rent.

"We need to buy a house for her."
Not necessarily. Owning property can affect benefits, funding and legal arrangements. Take advice first (Part 4).

"Shared Lives is only for short breaks."
It can be long-term, short breaks or day support.

"There is nothing we can do until she is older."
Planning can and should begin early, including in the transition years.





What comes next

Part 4: Future Planning explains appointeeship, the Mental Capacity Act, Lasting Power of Attorney, deputyship, and wills and trusts, so that families can plan for what happens when they are no longer able to support their son or daughter in the way they do now.



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