

## Preparing for supported living

Moving out is a major life change for anyone. When thinking about supported living, it's important to plan ahead. Planning ahead can help your son or daughter and you, adjust to the change. It can also help make the process smoother. Early teenage years are ideal to start introducing the concept of moving out of home, but into adulthood is good too.

It is important to make sure your son or daughter is properly included in the planning process. There are lots of easy read resources available to help your son or daughter understand what is happening and the choices they need to make.

Before you start putting anything in place, consider these things:

- Choices – do you know what your son or daughter's preferences are? E.g. Who do they want to live with? Where do they want to live? What's important to them?
- Being prepared – try to prepare your son or daughter for becoming more independent. What kind of skills do they need to learn? What support will they need?
- Change – moving out is a big step. Do they understand what living outside the family home will be like? Are there ways you can help them process this change?
- Support – how much support does your son or daughter need? What kind of tasks do they need help with? Who will provide this support?

## Thinking about moving out

Moving out is a big decision. Whilst your son or daughter might already be keen to have more independence, it's important to make sure that they understand what moving into supported living will mean for them.

Here are some ideas you can use to help your son or daughter start thinking about moving out:

- Ask what their ideal house would be like. It doesn't matter if their ideas are a bit impractical or outlandish – you can use this as a springboard to get them thinking about the idea and what they would like.
- Make a visual plan together of what's important to them, e.g. being near friends and family, going to college or work, being safe, living near leisure activities and parks, what they enjoy doing during the day, etc.
- If your son or daughter finds communication difficult, use visual aids, symbols, signing, 'talking mats' or photos to help them understand the choices and make a decision.

- Find some easy read resources on living in your own home and the choices you can make. You can find some easy read resources on the Housing and Support Alliance website.
- If you know anyone with learning disabilities who has experience of supported living, ask them to talk to your son or daughter about their experiences. You could also talk to someone you know who has experience helping someone with a learning disability live in their own home.

## **Making choices**

When thinking about moving out, there are some important choices to be made. Here are some key questions to consider with your son or daughter:

- Do you want to have your own home?
- Where would you like to live?
- What would you like to have in your home?
- 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?

Finding the answer to these questions will help you both make the right choices.

Your son or daughter may need support to understand and make a decision about these choices. Easy read tools; audio visual resources; images/ symbols; and adequate time to process information, are all useful aids that can help them make a decision.

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. The person can use this approach to select options about different choices, for example, where they want to live, whether they want to live alone or with friends, etc.

Sometimes people with Down syndrome aren't able to make a particular decision about where they want to live, or they may be unable to communicate their wishes. After work has been done to support them to make this choice, a decision then needs to be made following a best interests process.



## Putting a plan together

Once you have made some choices, you can start putting a plan together. This doesn't have to be an elaborate document – it can just be some ideas of what you want and what you need to do to achieve it. Here are some things to consider:

- Personal preferences
- The type of house
- Who to live with
- Who needs to be involved
- Where to go for information
- What support is needed
- Practical arrangements for moving in

## Developing skills

Before moving out, it's a good idea to think about whether your son or daughter needs some help developing new skills. For example, if they have always had their cooking and cleaning done for them at home, they may need some support learning how to perform these tasks more independently. Whilst they will probably still need some help, learning new skills to be able to participate in tasks around the home can improve independence and make moving into supported living easier.

It's important to remember that developing and building on independent living skills does not mean living without any support. Putting too much pressure on someone too soon can be overwhelming; in contrast, high but not unrealistic expectations with the right levels of support in place from the beginning will help to develop new skills and gain confidence.

If you are struggling to help your son or daughter develop new skills, here are some tips that may help:

- Think about where your son or daughter is now. What are their strengths? What do they find more difficult?
- Once you know what they can do, you can think about the kinds of living skills your son or daughter might need in their own home. For example, cooking a meal, shopping for food, tidying up, washing clothes, etc.
- Encourage your son or daughter to get more involved in household chores and tasks if they aren't already, e.g. helping load the washing machine.
- Whilst it's good to encourage independence, it's important to be realistic. Make sure your son or daughter gets the right support to help them with the tasks they are unable to do themselves.

- Most people with Down syndrome will need some level of prompting to do things. A support worker can play this role in the home.
- Visual aids and reminders can be used around the home to help your son or daughter remember what they need to do, e.g. the steps for making a cup of tea.

## Preparing for change

Moving out is a big change for anyone, particularly someone with Down's syndrome. Try to introduce them to the change gradually, so it doesn't become overwhelming.

To help your son or daughter understand the idea, try to normalise it. Acknowledge that whilst moving out is a bit 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, having more freedom, etc.

People with Down syndrome can have difficulties understanding abstract concepts, such as living in your own home, without having experienced it first. Providing your son or daughter with examples of people's lives can help. For example, they could talk to other people in the family who have moved out or spent time away from the family home, such as older siblings.

Despite the best preparation, when someone moves into supported living, there may be an 'adjustment' period, and your son or daughter may take a little time to settle in. This is not unusual, but having the right preparation and the right support in place will make the change easier.

## Your own feelings

As well as being a big step for your son or daughter, leaving home is also a big change for you as a parent. You may feel worried, anxious or sad about your son or daughter leaving home. You may feel that support workers won't be able to provide the same level of care that you do. This is quite normal and it's OK to feel this way.

Whilst there is always a sense of 'letting go' when your son or daughter moves out, you will still be very much a part of their life and support network. As a parent, you know your son or daughter best and should be fully involved in the support planning process and support staff should listen to and value what you say.

Some people choose to move into supported living placements very close to home, so that the support network of family and friends is always close by. This can sometimes help make the transition easier. However, this option is not always possible for everyone.

Whatever you choose to do, it can help to remember the reasons why your son or daughter is moving out, and the positives that change can bring. For example, living more independently can help your son or daughter gain independence, new skills and confidence, and meet new people without losing a close relationship with their family.

## **Different types of support**

There are several different ways your son or daughter can get support in supported living. Here are some of the main forms of support people with Down syndrome in supported living receive.

## **Support workers**

Many people with Down syndrome who live in their own homes receive support from support workers in the home. If your support is funded through an ISP or NDIS, the amount of support you receive will depend on your son or daughter's needs.

Support can be available for 24 hours a day if that's what is needed. Other people may only need support workers to visit at regular intervals during the day. Some people may need support workers staying overnight, whereas others may not need overnight support. The important thing is that the level of support is tailored to the individual.

## **Circles of support**

Circles of support can be another way of adding an extra layer of support. A circle of support is a group of people who know a person well, such as family, friends and supporters, who meet regularly to help the person they support achieve what they want. This can include sharing ideas to tackle problems, providing a strong network of relationships, helping the person feel more independent and taking action to get things done.

A circle of support usually includes somewhere around 3 – 10 people. They can include friends, family and other people who know and support the person. There is no formal process to setting up a circle of support and you can organise it yourself.

If you would like more information about circles of support and what they involve, the Foundation for People with Learning Disabilities has a factsheet

[www.learningdisabilities.org.uk/our-work/family-friends-community/circles-of-support](http://www.learningdisabilities.org.uk/our-work/family-friends-community/circles-of-support).

Other information on Circles of Support:

<http://www.resourcingfamilies.org.au/building-support-networks/>



## **Lead tenants**

Lead or support tenants are tenants who live with a person with a learning disability and provide them with support as part of their tenancy. A Lead tenant can provide support with household tasks and budgeting, as well as other forms of support to help with independence.

Lead tenants have a contract that specifies particular support duties as part of their tenancy. This can include being in at certain times of day, offering support with daily living tasks such as helping prepare meals and notifying the support provider when they will be away.

In exchange for their support duties, Lead tenants may not have to pay rent and may receive reasonable expenses for their support duties.

If you would like more information on support tenancies, <https://www.unitingcareharrison.org.au/>

## **Shared Lives arrangements**

A Shared Lives arrangement is when a person lives with another family. The person tends to have their own room, but shares other spaces in the house. Many Shared Lives schemes have been set up in the UK and it is an idea that is starting to be put into practice in Australia, but is still new here.

You can find out more about Shared Lives on the Shared Lives website: [www.sharedlivesplus.org.uk/about-us/shared-lives-about](http://www.sharedlivesplus.org.uk/about-us/shared-lives-about). You can also find information on the Housing and Support Alliance's online factsheet:

[www.housingandsupport.org.uk/shared-lives-and-supported-lodgings](http://www.housingandsupport.org.uk/shared-lives-and-supported-lodgings).

## Getting the right support

Getting the support right is key to successfully moving into your own home. The level of support given should reflect what the person with Down syndrome needs. These needs should be developed as part of their future plan.

Start thinking about what kinds of tasks your son or daughter will need to do in supported living. These could be:

- Cooking meals
- Shopping
- Handling money/budgeting
- Cleaning/tidying
- Personal care
- Travelling around/using transport
- Taking part in leisure/social activities
- Getting ready for work/college/going out
- Taking medication

Sometimes people are able to do a task but they will need prompting to do it or plan the steps to do the task. This is still something they need support with and can be part of the support your son or daughter receives.

With the coming of NDIS there is potential for support needs to be provided by support workers, who you can source to assist in developing independence. Having a proper, thorough and balanced plan is the key to getting the right support put in place.

In developing future plans, it's important to think about what your son or daughter needs help with, and how much help they will need.

Even if your son or daughter seems more independent, it's important to have enough support in place. Starting off with a higher level of support can help your son or daughter feel secure and able to cope. Social services can then test and reassess your son or daughter's needs at different points further down the line.

## Funding

NDIS will be the way of the future in funding for supports. Individual plans will be developed collaboratively, between the young person, their parents and a planner. Starting to think about future supports is a useful thing to do now, even if NDIS won't be in your area for a few years.

## **Personal budgets**

A personal budget is an amount of money set aside, based on the needs stated in the person's plan. You can choose how the money is spent, as long as your planner agrees that it is meeting the person's goals.

Personal budgets can be used to fund support for supported living. Personal budgets aim to give you more choice.

## **Remember - the road to independence is not always a straight one!**

Sometimes people think that the road to independence is a straight one, starting off with a low level of independence that increases over time and ends up with a person who needs little or no support. This isn't usually the case. For example, some people may start off seeming very independent, but need more support at a later point. This is absolutely fine. It is also important to remember that everybody is unique and will need different levels of support for different things. That is okay too.

It's therefore vital to have enough support in place to meet someone's actual, rather than their perceived, needs. Having more support is far preferable to having too little, since not having enough help can lead to a person feeling overwhelmed, stressed and anxious. If left for too long, such a situation can reach crisis point. However, putting the right support in place from the beginning goes a long way to ensuring that sort of situation doesn't occur.

## **Down Syndrome Victoria**

Down Syndrome Victoria provides information and support on all aspects of living with Down syndrome. We also work to champion the rights of people with Down syndrome

### **Contact us**

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