



## **Making Supported Living Work for People with Down's Syndrome**

Information for Support Staff



**A Down's Syndrome Association Publication**

## The Down's Syndrome Association (DSA)

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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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**We have made this resource to help you if you are supporting a person with Down's syndrome. It contains some basic information about Down's syndrome, details of some of the difficulties people may face and tips about how you can support a person to overcome these difficulties.**

Remember, no guide can replace you getting to know the person by talking and listening to them and by building a relationship with them. If you would like to discuss any of the points made in this guide or you have questions about someone you are working with, please call our helpline on 0333 1212 300.

## **What is Down's syndrome?**

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Down's syndrome is a genetic condition that is present from birth. The condition is caused by the presence of an extra copy of chromosome 21 in a person's cells. Everyone with Down's syndrome has a level of learning disability.

## **Learning disability**

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Having a learning disability means that it takes longer to process information and to learn new skills, tasks and learning may need to be broken down into smaller steps. People with a learning disability may not learn things as quickly as other people and they may need more help and support to learn. Some people with Down's syndrome will have a greater level of learning disability; this may be due to an additional diagnosis, an additional health issue or just because this is how the syndrome has affected them.

## Difference and similarity

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The effect that the extra genetic material has on each person's health and development varies a lot. Everyone will have some additional needs, but the way the syndrome affects an individual will be different from person to person. People with Down's syndrome share some common physical characteristics, but they do not all look the same. Each person you support will have a unique personality.

Although each person is different, people with Down's syndrome share certain ways of learning. They have strong visual learning skills; they are good at learning by watching and doing and find it harder to learn by listening. Use hands on practical experience, pictures, photos and films to help a person with Down's syndrome learn new information and skills.

People with Down's syndrome are individuals and they will be affected by the issues we discuss in this resource in different ways. The people you are supporting are adults and should be treated as such. They are adults who may sometimes do things a little differently, who may confuse you a little at times and who may just need a bit of extra help and understanding to fulfil their goals, ambitions and dreams.





## People will surprise you – keep an open mind

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Never assume that someone does or does not understand and that they can or cannot do something. Have high but realistic expectations. You need to keep re-thinking about what is possible for the person as they grow and develop. Some days all might go really well, some days they may not be able to do things as well as yesterday and tomorrow they might well do something you didn't know or think they could do at all.

*Example: A woman who lives in her own flat is supported day and night by a team of support workers. Every day, they used to cook for her and she used to assist with small tasks. One day her support worker was delayed because of traffic. When she arrived well after the woman's dinner time, the woman had cooked a meal for herself and was sitting eating it.*

## We all need boundaries – treading the line between sharing information and respecting privacy

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It is helpful for you to think about your role in the person's life; first and foremost you are there to support the person to lead the life they wish to lead. Bear in mind that you are in that person's life as a friendly professional not a professional friend. Families, friends and other professionals can often give you vital information about a person. They can offer tips about what works and what doesn't so it's good to try and form a relationship with those who know the person you are supporting well. Information about their communication and what causes them anxiety will help you provide the best support.

Remember the individual you support may not want other people to know everything about their lives so their wish for privacy and confidentiality must be respected. You may be called upon to support the person to keep an aspect of their life private through mediation with others in their life.



## Relationships

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As with most of us people with Down's syndrome have and want relationships of all kinds; these may be friendships, partners of the opposite or same sex, or sexual relationships. Some may find it hard to acknowledge that the person you support is a sexual being with their own desires and preferences. It is important that you are comfortable with these issues so that you can provide appropriate support; even if it is only a listening ear when worries arise. This may be an area where you will be called upon to mediate with families.

The person you support may have a wide network of people with whom they have built relationships on many different levels. However, what many people with Down's syndrome struggle with is developing and maintaining friendships and relationships. They will probably need your help to arrange meeting up with their friends and with developing their social lives and social skills.



## Learning by seeing and doing

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People with Down's syndrome are really good at learning new information and skills through watching and copying. This is sometimes described as having a strong visual memory. If you are helping someone to learn a new skill:

- Show them how it's done
- Talk them through the task
- Break the task into small steps
- Get the person to have a go
- Give the person chances to practice over a period of time to consolidate the skill.





Photos and pictures can really help a person to learn new information and keep on track with tasks on a daily basis. Everyone with Down's syndrome has poor visual acuity. Visual acuity is still poor even when a person with Down's syndrome is wearing correctly fitted glasses for either long or short sight. What this means is that their world lacks fine details and sharp contrasts.

You can help the person you support by making sure that all the materials and images that are used to teach and support them on a daily basis are big and bold. For more information about this issue and useful resources go to:

<http://www.downs-syndrome.org.uk/policy-and-campaigns/vision/visual-acuity-thing-big-think-bold/>

People with Down's syndrome can sometimes surprise you by telling you in great detail about something they have seen and experienced. This has been described as similar to having a video camera switching on in a person's head providing a perfect image of what they once saw.



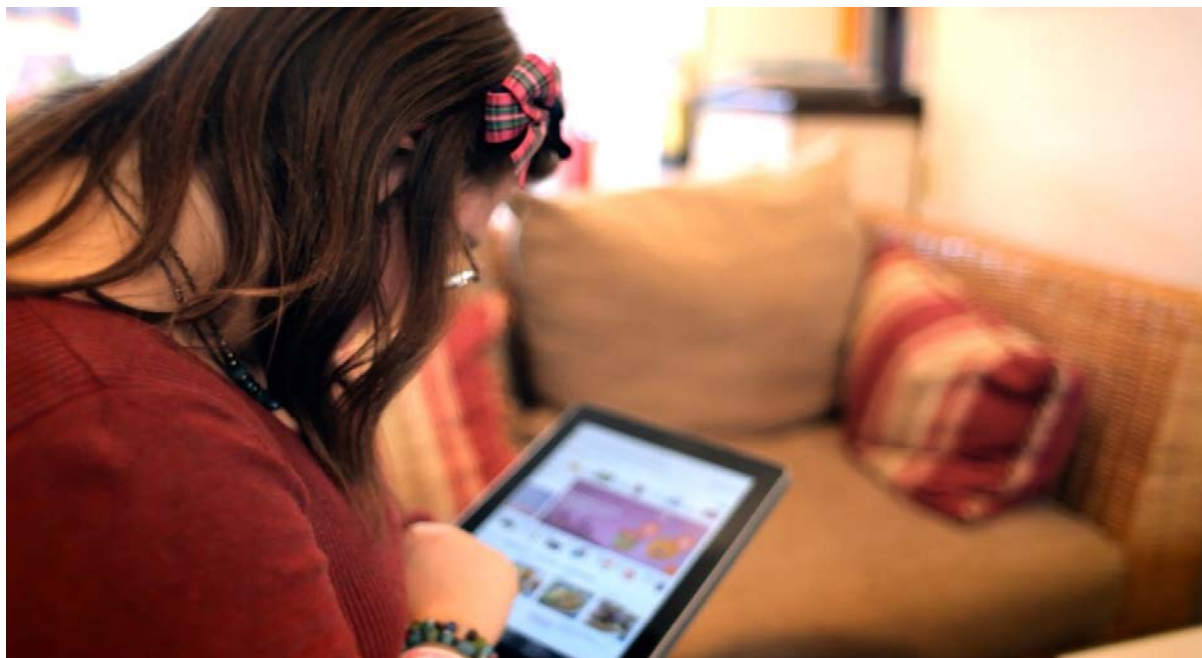


## Modelling skills and behaviours

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People with Down's syndrome can learn new skills by watching, copying and doing but may also copy behaviours or actions they are not aware are bad or inappropriate. If you are saying one thing to a person with Down's syndrome about how they should behave but behaving differently, this can send mixed messages. The person will either be very confused or will just pick up on the message given by your behaviour rather than the spoken message you have given.

*Example: a young adult with Down's syndrome got a voluntary work placement at a day centre for people with dementia. Staff explained to her what she was there to do and showed her what her tasks were. They were very clear that she shouldn't stroke or touch the people at the centre. However, the same day a nurse at the centre commented on the woman's lovely hair and brushed and styled it for her. The message that she took away was that this was an appropriate way to behave at the centre. She just couldn't understand when she was told off for touching the service user's hair.*



## Time to think

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Try to give people time to think about and respond to what you are asking or telling them. Most people will find it difficult to change the rate at which they take in information in different situations. They will struggle if they need to suddenly speed up with an activity. Responding to an urgent situation may cause them to become stressed. As a result, people with Down's syndrome generally prefer routine and they find change difficult to deal with. Some people may actually slow down or stop if they feel that they cannot cope with all the demands and information that is coming their way.

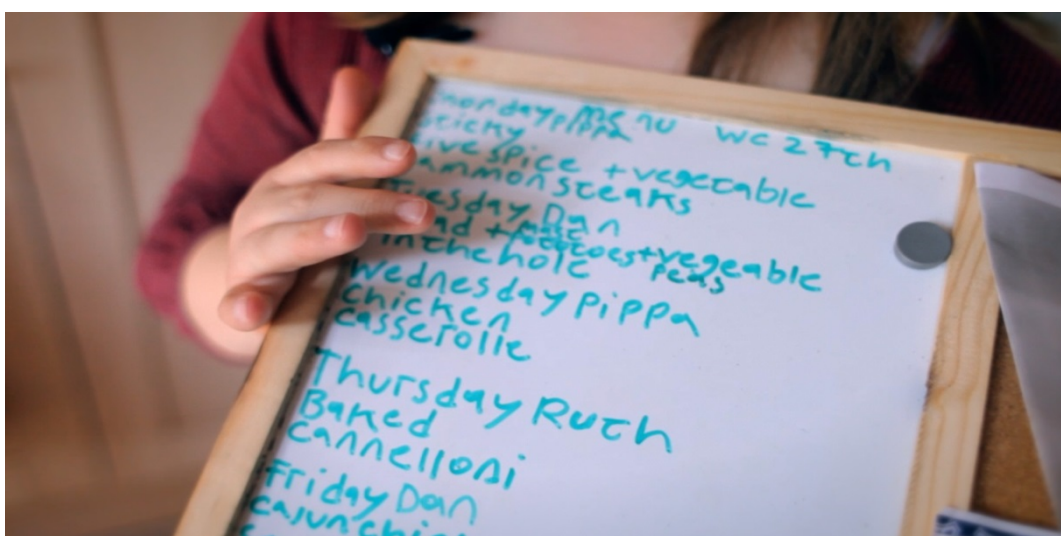
*Example: A woman with Down's syndrome is being helped to monitor her insulin levels with mum talking to her on the phone and her support worker standing with her and talking to her at the same time. The woman suddenly freezes with the phone and blood monitor in her hand. The solution was for one person to stop talking and for the other to give clear slow instructions in a reassuring way.*

## Thinking about communication – yours ...

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Because people are not always as good at taking in information through listening, think about the words you are using. Could your language be made simpler and easier to understand? Try to remember to avoid jargon, to speak clearly and use shorter words and sentences. If someone doesn't understand, try asking the question in another way. Check that the person has understood and, if necessary, repeat what you are telling them. Use visual prompts and reminders where you can.

*Example: A man with Down's syndrome was working in an office and he was encouraged by a colleague to 'call any time'. So he took the person at their word and called them at home at 3am several times. The colleague and other workers at the office then had to have a think about the language they used and tried to use language that couldn't be misunderstood by the man with Down's syndrome.*



## ... and theirs

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People with Down's syndrome sometimes find it hard to use spoken language to explain their thoughts and feelings. Some people are good at using spoken language whilst others have little or no speech at all. However, most people fall somewhere in the middle; they use speech as their main way of communicating but they may have difficulty in being understood by people who do not know them well. Those with little speech may use sign language like Makaton or communication aids like PECS. Games and role-playing can be a useful way of helping people to express how they are feeling. Once you have carefully listened to what someone is telling you, reflect back to them what you think they have said 'I think you said ... is that right?' This may help you to find out if you are on the right track.

Always try and ask yourself if a person's behaviour is conveying a different message to the one they are speaking. Remember that behaviour is also a way of communicating worry, emotion, fear, unhappiness and ill health. Don't always take the first answer that someone gives, they may be telling you what they think you want to hear!

Getting to know a person over time and learning from them and their families will help improve how you communicate with them.



## Staying on track through routine and repetition

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Once people have learnt a routine they are really good at sticking to it. Routine helps people know what is happening next and it helps to maintain order making the person feel safe and secure. It's good to know that people have this tendency and to work with it. However, keep an eye, for situations where the need for routine begins to increase and interfere in daily life. This can be a sign that a person is feeling unhappy or worried about something.

*Example: A young woman moved from the family home into a supported living placement. After a couple of months her routine around using the toilet began to interrupt her daily life; her visits to the bathroom increased to the point where she was using it every 20 minutes. This routine made her feel safe. The woman's support worker took her to see her GP to check if there was any medical reason for the behaviour. Once a medical cause had been ruled out, the support worker spent time talking to the woman, her family and colleagues. Together they concluded that the woman probably needed more support and structure on a daily basis than they had originally thought. A new care plan was put in place and the woman's reliance on this ritual slowly reduced.*

It's time to seek help from other professionals if you feel that someone you support is becoming so reliant on a routine or ritual that it is affecting their quality of life.

## Doing something new

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People sometimes struggle with new and unfamiliar activities and places. Understandably, some people will try to avoid new experiences because they are unable to imagine what that new experience might be like. Most people with Down's syndrome need some preparation, plenty of time, and support to deal with change and new experiences. You can help a person prepare by talking to them over time about a forthcoming change or new event and by using pictures and film.



*Example: A man with Down's syndrome needed to go the hospital for the first time. His support worker talked to him about what was going to happen and then she arranged for him to have a trial visit to the hospital and to meet the doctor who was going to treat him. Whilst they were at the hospital they took some photos of the building. When they got home they made a story book using the photos as a reminder for the man about what to expect when he went to hospital. They also used one of the photos on his visual timetable.*

## What's the risk?

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We all assess risk, often without consciously thinking about it, for the activities we do every day. As a support worker for vulnerable adults you will be thinking about risks for the person you support so the process of assessing risk needs to be formalised. This does not have to be a difficult or lengthy process and it can help both you and the person you support to recognise potential risks. Neither does it have to just focus on negatives. It can help you to focus on the benefits of taking a risk which might lead to a person having new experiences and learning new skills which they might otherwise have missed out on. For example, this might be the benefit of learning to travel a particular route independently, and the positive self-esteem created by this process, weighed against the worry that a person might get lost when they first try to travel alone.



## Transferring skills to new environments

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You cannot assume that because a person has learnt a new skill at home that they will be able to put that skill to use elsewhere. People with Down's syndrome find it more difficult to transfer skills from one situation to another. A good strategy to help them overcome this difficulty is to find different ways of repeating the same skill in a variety of contexts. People with Down's syndrome find it easier to learn from doing and in real life situations.

*Example: an adult who has received travel training to take the bus to and from his place of work on a Wednesday was unable to accept and understand that he could take the same bus to work on a different day. The man's support staff took time to travel to and from his workplace on different days. In this way he learnt that he could travel on the bus to and from work any day during the week.*

## Who are they talking to?

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Many of us talk to ourselves sometimes, but it seems to be quite common for people with Down's syndrome to talk to themselves regularly. In most cases, it's nothing to worry about. People are thinking aloud, maybe talking through events of the day, working out a problem, talking themselves through a task, or even just entertaining themselves or letting off steam. In fact, it can be useful to listen in every so often to find out what's going in a person's life and to know if anything is worrying them. If there is an increase in a person talking to themselves and/or changes to where they are doing it and what they are saying, this might indicate that something is wrong.

Some people may indulge in a bit of fantasy and talk to themselves about their favourite TV soap or pretend that they are a character in the programme. This can be harmless and you should just be aware that this happens. Sometimes people live a little through soap operas and the line between fiction and reality can become a bit blurred. If you notice that a person is using frequent negative self-talk and/or their fantasy life is becoming overwhelming and spilling into all areas of their life, it's a good idea to think about getting advice from the local Community Learning Disability Team.



## Time

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Some people may be very good at describing in detail a past event that they witnessed but if you ask them when it happened, they are likely to find that quite difficult to answer. The idea of past, present and future can be very hard for people to understand and causes confusion. People may have a different understanding of time. Knowing that a person might talk to you about a past event as if it has just happened can prompt you to ask them more questions and hopefully avoid confusion. Sometimes if you ask questions to try and locate where something happened, you can get to the bottom of a situation (e.g. did that happen at college? – they only go to college on a Monday so you have narrowed the time window down).

*Example: a woman with Down's syndrome will tell you that her mother has died and it is obvious that she is very much feeling that this has just happened. Mum actually died about 20 years ago but the difficulty in placing that event in time, combined with her ability to vividly recall a picture in her mind of when that happened, make it feel to her as if it just happened.*

Visual timetables can be very useful to help the person know what is happening next, what they need to do and where they need to do it. A visual timetable helps people to understand what they are doing over a period of time such as a day. They give a structure and can help to reduce a person's anxiety about what is happening next. A mixture of symbols, photos and the written word can be used (according to individual need) to represent the tasks and activities for that day.

## **We all have off days!**

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This is no different for people with Down's syndrome. If people are worried or unhappy, this will sometimes make it harder for them to concentrate and to take in information. Are people trying to let you know in other ways such as a change in behaviour that things are not right for them? Are they being asked to make too many choices at once without help instead of being given fewer choices with some support to make them? Sometimes a person's ability may change and they might not be able to cope with something or do a task that they could do only last week. It is important to just keep an eye out for this. Is the person unwell? Are they unhappy or stressed? Is too much being asked of them too quickly? Do there need to be some changes in their surroundings or the way in which they are being supported?

## **Good Health**

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People with Down's syndrome have a right to good physical and mental health. A healthy lifestyle with regular exercise and a good diet are just as important for people with Down's syndrome. As previously mentioned people with Down's syndrome tend to be very routine-orientated, so including healthy living in the daily routine is a good way to establish a healthy lifestyle. Exercise is important, but the good news is that it doesn't have to look like exercise in the traditional sense; activity is the important part rather than the location! Fun recreational social activities can provide the benefits of exercise without feeling too much like hard work. Building regular walks with friends into the week can really help. Getting a voluntary or paid job might also provide opportunities for activity. Have you heard about DSA's WorkFit programme for people with Down's syndrome? More information at: [www.dsworkfit.org.uk](http://www.dsworkfit.org.uk)

Social activities such as dancing or drama groups can be really good motivators for people with Down's syndrome. Exercise DVDs, particularly those featuring a favourite actor or TV personality, or Wii fitness or Wii workout are enjoyed by many adults. Putting visual reminders around the house can also prompt the healthy living routine. Take a look at DSA's DSAActive website to find out if they are running an adult sports programme in your area: [www.dsactive.org](http://www.dsactive.org)

It's important to remember that people with Down's syndrome can be supported to understand how to look after their own health. Simple ideas such as traffic light labelling systems, knowing the difference between junk and healthy foods and selecting fruit and vegetables can all help. If you would like more support with this, there are easy read resources available on healthy eating and exercise - you can download these from the DSA website: [www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being/healthy-living-guides](http://www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being/healthy-living-guides)



- People may not always be able to let you know that they are unwell. It may be their actions rather than words that tell you that something is wrong.
- You can help the person you support by being aware of the health problems that are more common in people with Down's syndrome. The DSA can help you with this.
- Did you know that in addition to routine appointments, adults with Down's syndrome are entitled to a free comprehensive and thorough annual health check with their GP?



We have produced the following resources to help you and the person with Down's syndrome whom you support:

- Adult Health Book. Free to all adults with Down's syndrome who are members of the DSA. Membership is free to all adults with Down's syndrome. See [www.downs-syndrome.org.uk/membership-join-the-dsa/person-with-downs-syndrome](http://www.downs-syndrome.org.uk/membership-join-the-dsa/person-with-downs-syndrome)
- Annual Health Checks for Adults with Down's syndrome: Check List. Free to download at [www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being](http://www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being)
- Health Series of Publications. Free to download at [www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being](http://www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being)
- Website for GPs with information about the more common health conditions that are seen in adults with Down's syndrome [www.dshealth.org](http://www.dshealth.org)
- Sit down with the person you support and take a look at the health section of our website for people with Down's syndrome [www.downs-syndrome.org.uk/for-people-with-downs-syndrome](http://www.downs-syndrome.org.uk/for-people-with-downs-syndrome)

## Changing Needs

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The needs of people with Down's syndrome will change as they progress through life. They are now living into their fifties and sixties with small numbers of people reaching their seventies and beyond. It is important to know that some people may experience physical ageing and age-related health problems at an earlier stage than is seen in the general population.

For example, cataracts, osteoporosis and gum disease appear to be more common and occur earlier in people with Down's syndrome. Like the general population, people with Down's syndrome may need more support as they get older. You can learn more about ageing with Down's syndrome at our website <http://www.downs-syndrome.org.uk/for-families-and-carers/adulthood/getting-older/> Our booklet 'Ageing and Its Consequences' is free to download at this link.

Alzheimer's disease is a frequently voiced concern about people with Down's syndrome. Alzheimer's disease is a type of dementia that gradually destroys brain cells, affecting a person's memory and their ability to learn, make judgments, communicate and carry out basic daily activities. Alzheimer's disease is characterized by a gradual decline that generally progresses through three stages: early, middle and late stage disease.

There is a tendency for people with Down's syndrome to develop Alzheimer's disease at a younger age than is seen in the general population. However, it is not inevitable that those with Down's syndrome will develop it. If you notice any changes / deterioration in the person you support, do not automatically assume that they are developing Alzheimer's disease. Many of the health conditions that are more common in people with Down's syndrome can be mistaken as Alzheimer's disease if not identified properly (e.g. hearing loss, low thyroid function, vision loss, B12 deficiency, sleep apnoea, depression). Since these are treatable, it is vitally important for the person to have a full medical assessment at an early stage in order to rule them out.

Further information about Alzheimer's disease can be found at our website:

<http://www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being/dementia-alzheimers-disease/>

Our booklet about Alzheimer's disease is available to download at this link.

## Everything has a reason

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Whatever a person does, there will be a reason. Sometimes as their support worker you have to be patient and act like a detective to try and work out what is going on with a person and what, if anything, they are trying to communicate. You don't have to do this on your own; talk to friends and family and call the DSA on 0333 1212 300 or email [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk). We don't claim to always have the answer but sometimes it can help to talk through a situation with somebody who isn't directly involved in it.

## Becoming a member of the DSA

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Please let the person you support know that they can have free membership of the DSA. They can join online at [www.downs-syndrome.org.uk/membership-join-the-dsa/](http://www.downs-syndrome.org.uk/membership-join-the-dsa/)

If they decide to join, they will receive the Down 2 Earth Magazine which is by people with Down's syndrome and for people with Down's syndrome. More information about the Down 2 Earth Magazine can be found at [www.downs-syndrome.org.uk/for-people-with-downs-syndrome/down-2-earth-magazine/](http://www.downs-syndrome.org.uk/for-people-with-downs-syndrome/down-2-earth-magazine/)

You may also like to think about joining the DSA. Here are some of the ways that joining the DSA would benefit you as a support worker:

- You will receive our Journal which contains information and news that will be relevant to the people you support
- Free copy of each of our publications on request
- Access to expert advice on all aspects of living with Down's syndrome
- Information about our Conferences and Training programme covering a range of topics to help with your professional development
- Information on new research
- Up-to-date relevant information resources





## Useful Resources

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### Down's Syndrome Association Publications

#### Supported Living Series

Supported Living Videos here <http://www.downs-syndrome.org.uk/for-families-and-carers/social-care-support/supported-living/supported-living-video-series/>

Factsheet 1 – Supported Living FAQs – Thinking about supported living

Factsheet 2 – Supported Living FAQs – Handling problems

Factsheet 3 – Preparing for Supported Living

Factsheet 4 – Principles for Supported Living

Download factsheets at:

<http://www.downs-syndrome.org.uk/for-families-and-carers/social-care-support/supported-living/>

#### Making decisions/mental capacity

You can read about making decisions and mental capacity at <http://www.downs-syndrome.org.uk/for-families-and-carers/social-care-support/supported-living/>

### Other organisations

#### Foundation for People with Learning Disabilities

Thinking Ahead: a planning guide for families

<http://www.learningdisabilities.org.uk/our-work/family-friends-community/thinking-ahead/>

#### Housing & Support Alliance

Information about housing, support and your rights | <http://www.housingandsupport.org.uk/easy-read>

### Easy Read

#### The Emergency Communication Book

[www.communicationpeople.co.uk/services/the-emergency-communication-book/](http://www.communicationpeople.co.uk/services/the-emergency-communication-book/)

#### Books Beyond Words

Beyond Words produces books, eBooks and other resources for people who find it easier to understand pictures than words | [www.booksbeyondwords.co.uk](http://www.booksbeyondwords.co.uk)

#### Easyhealth

Free easy read information about health | [www.easyhealth.org.uk/](http://www.easyhealth.org.uk/)

#### Foundation for People with Learning Disabilities

A Guide to Circles of Support | [www.learningdisabilities.org.uk/publications/guide-circles-of-support/](http://www.learningdisabilities.org.uk/publications/guide-circles-of-support/)

#### Housing & Support Alliance

Information about housing, support and your rights

<http://www.housingandsupport.org.uk/easy-read>





[www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)  
[downssyndromeassociation.wordpress.com](http://downssyndromeassociation.wordpress.com)  
[www.facebook.com/DownsSyndromeAssociation](https://www.facebook.com/DownsSyndromeAssociation)  
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[www.dsactive.org](http://www.dsactive.org)

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[www.dsworkfit.org.uk](http://www.dsworkfit.org.uk)



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[normansfieldhospital.wordpress.com](http://normansfieldhospital.wordpress.com)  
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Langdon Down  
centre

<http://langdondowncentre.org.uk>



## Down's Syndrome Association

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### Northern Ireland

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