DOWN'S SYNDROME ASSOCIATION

Social Care and Support

Common Issues

August 2025



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 who have 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 dietitian can provide further support around portion sizes.

Our healthy living factsheets can be found here.





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 (provide evidence if you have it) and come up with a plan to tackle them. You may like to show them our resource for support staff, Making Supported Living Work for People with Down's Syndrome.

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. Under the Care Act 2014, local authorities must carry out an assessment where it appears that an adult may have needs for care and support, regardless of their finances or eligibility (Section 9). If circumstances have changed or a previous assessment did not fully reflect needs, you can request a reassessment (Care Act Statutory Guidance, paragraph 6.27). You will find further information about social care assessments on our website here. If your relative has substantial difficulty being involved in decisions and has no appropriate person to support them, the council must provide an independent advocate to help with assessments, care planning and safeguarding (Care Act 2014, Sections 67–68).

If the support is funded by the local authority and you can't resolve the issue informally, you can 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. Complaints to the local authority should normally be responded to within 20 working days (Local Authority Social Services and NHS Complaints Regulations 2009). There is information about making a complaint to your local authority on our website here.

If you are unhappy with the response, you can escalate your complaint to the Local Government Ombudsman.

Information for Support Staff



You may find that some of your relative's support staff have not had contact with a person who has Down's syndrome before.

We have produced a guide with suggestions about supporting people which you can download from our website here.

Handling Staff Turnover

Increasingly families are contacting us to express concerns about high levels of staff turnover. This can be quite difficult for your relative to cope with if not handled properly. Person-centred planning can help - there is information about support planning at our website here.

Here are some ideas for supporting a person through the loss of a support worker:

- Make time and space for questions.
- Maintain routine and consistency.
- Keep the person busy.
- Check to see how they are doing and provide positive distractions if you think they are perhaps over focusing on the support worker leaving.
- If possible, bring in the new person before the old support worker leaves - plan for them to work alongside each other.
- Make sure the new staff member has adequate information about your relative to ease the transition.
- New support worker takes over as the old support worker's input tails off.
- Try and mark the occasion with a leaving event/party.
- Monitor how the person is doing. Some people may take time (e.g. perhaps 6 months or so for some people) before they feel sadness and a sense of loss – continue to give support and understanding.

New and Different Behaviour

Sometimes people who have 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 may feel overwhelmed if given too many choices and 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 their behaviour has changed, try to talk to them in the first instance. Visual aids may be helpful if they find it hard to use spoken language to explain how they are feeling or what has happened. If needed, you can 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 support staff are aware of our health and wellbeing resources. You'll find them at our website here.

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

The changes associated with moving into supported living can lead to some people experiencing anxiety or depression. If you are concerned that your relative is experiencing depression, make sure he or she sees their GP. There is information about depression on our website here.

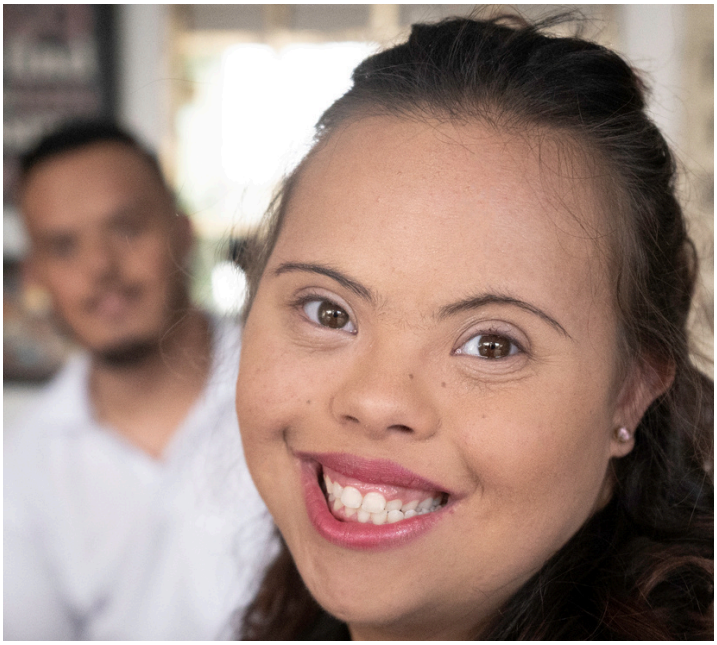
Issues with Housemates

Just like any group of people living in one place, there can be arguments or disagreements in your relative's household. However, sometimes these issues 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. Local authorities have a legal duty under Section 42 of the Care Act to make enquiries if they reasonably suspect that an adult with care and support needs is at risk of abuse or neglect. This duty applies even if the person does not meet the eligibility threshold for care and support.

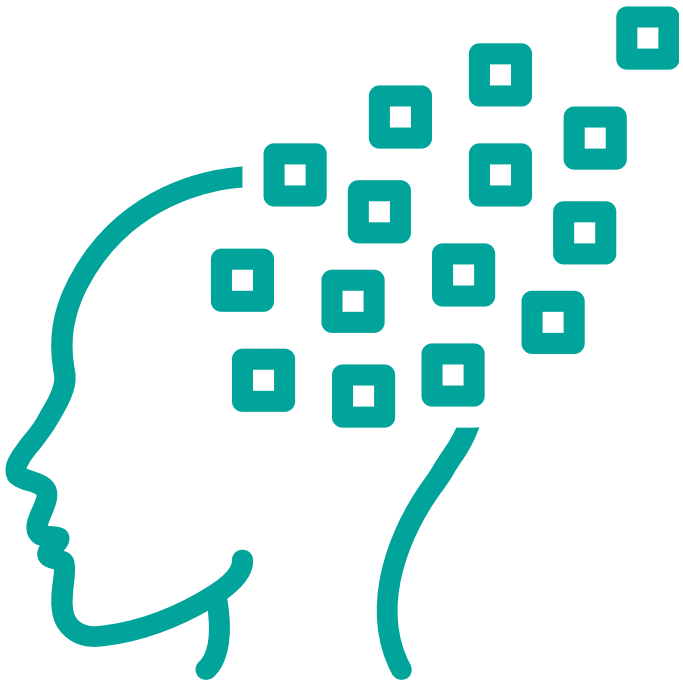


Dementia

Families are sometimes concerned about dementia. Whilst people who have 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 issues that can be mistaken for dementia. 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. There is information about dementia on our website here.



We Can Help

If you have any questions about social care, please contact us using Tel: 0333 1212 300 or Email: info@downs-syndrome.org.uk. If our information officers are unable to help, they will refer you to our social care adviser.

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