



Social care and support

Common issues

Date: August 2020

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.

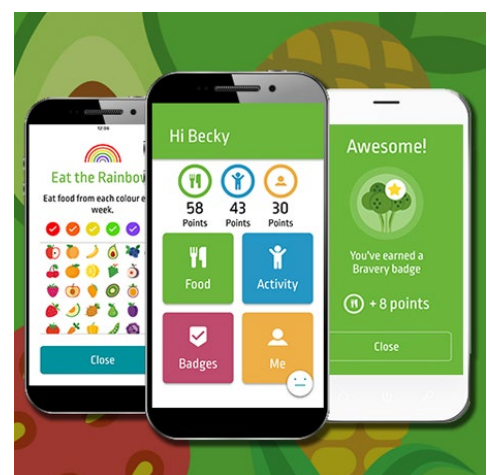
Sometimes support workers and carers feel that they have to allow your relative to eat unhealthily to avoid restricting freedom of choice. This is not necessarily the case. Your relative may still need to be supported to make decisions about his or her diet, which could include visual reminders about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

We have produced [the Health Swap App, a healthy living app](#), to help people with Down's syndrome to make positive changes to their lifestyle through healthier eating and activity tracking.

We have also developed [some healthy living factsheets](#).



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*.

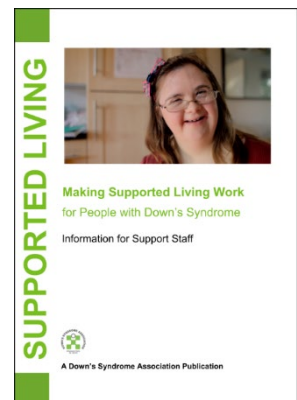
If this approach does not work, contact your relative's social worker and raise your concerns in writing. If you feel your relative's needs are not being met or have not been assessed correctly, you can ask for a full social care reassessment of his or her needs. You will find further information about social care assessments on our website here.

If the support is funded by the local authority and you can't resolve the issue informally, you can formally complain to your local authority. We strongly suggest that you complain in writing, as this is more likely to lead to a satisfactory response. Your local authority must have a formal complaints procedure on their website. There is information about making a complaint to your local authority on our website.

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 as to how best to support people who have Down's syndrome which you can download from our website.



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

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

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. You'll find them all the information on our website.

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

The changes 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.

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.

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.

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.

Contact us

t. 0333 1212 300

Down's Syndrome Association

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