

Education

Supporting teenagers

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Teenagers who have Down's syndrome go through the same physical and hormonal changes at around the same time as other teens. This is a time when they will want to be doing more for themselves. It is a time for testing the water as to what is possible and when.

In common with other teenagers, young people may seek more time away from parents with more time spent in their own personal spaces such as their bedroom. Depending on what individuals know already, there may be a need both at home and school to re-visit and reinforce knowledge around public and private behaviour.

Skills and level of development vary greatly from one person who has Down's syndrome to another. Some people will try to do things at roughly the same time as other teenagers, but the majority will be at a different level of skill to other teenagers of a similar age. Some teenage behaviours may carry on for longer than might be seen in the general population or they might disappear and reappear at a later time. This may be because their pattern of development is a little out of sync. Physical bodily maturity may have overtaken other areas of development which are still catching up.

Being a teenager can be a confusing business, with hormones raging, lessons to be learned and mistakes to be made in abundance. People who have Down's syndrome have to navigate additional complications such as being unsure, or unaware of, the rules and boundaries and finding it difficult to express thoughts and feelings. In some teenagers there will be a growing awareness of difference and being treated differently; this is often triggered when siblings/friends begin to do things that they are unable to do without support.

Teenagers in the general population will often pick up on information and lessons about growing up, relationships, behaviour and expectations in an informal way from their friends, peers and the media. It isn't so easy for people who have Down's syndrome to do this; information, ideas and lessons might be missed or misunderstood.

This article covers some of the areas around which teenagers will require support and input both at home and school to varying degrees. Effective home/school liaison, sharing of information, and adoption of the same approaches will go a long way to ensuring teenagers receive the support they need as they grow and develop.

Personal hygiene and grooming

During puberty young people will need teaching about hygiene and personal grooming. As with any learning, repetition, showing through doing, visual supports (such as picture schedules), easy-read information, breaking down tasks/information into manageable segments and hands-on practice are really helpful for people who have Down's syndrome. Always use proper terminology, simplify language without dumbing down and be consistent with the messages/lessons that are being conveyed.

Some teenagers might resent a parent's input so it can be helpful, where appropriate, to find a trusted family member (perhaps a sibling or cousin) whom they look up to teach certain tasks. Self-esteem and confidence will be boosted as young people learn to do some self-care tasks themselves.

People who have Down's syndrome are really good with routines (sometimes known as grooves). Once a person has learnt a successful self-care routine they will carry on with it; positive routines should be supported and encouraged.

A sense of competence

Developing competence is about focusing on what can be done, emphasizing a person's strengths and skills and building on them. At home, this process starts in the early years and continues with supporting the person to learn and practice self-care skills and then daily living skills. As we get older, we all want to do things for ourselves. This gives us a greater sense of independence and control over our daily lives and enhances feelings of pride and self-esteem.

When choosing new tasks, think about what the person is physically able and developmentally ready to do. Try to have high but realistic expectations; if they are too high or too low, this can lead to frustration, failure and/or underachievement. It can be a balancing act because, like everyone else, people who have Down's syndrome need to be able to learn as a result of trial and error and making mistakes. You will need to think about how such situations are managed so that people are exposed to manageable levels of frustration that don't put them off achieving what they set out to achieve. Think about creating opportunities where the person is able to take on some responsibility and/or is able to help others. Meaningful achievement will be different for each person; a small step for one person might be a very big step for another.

As people who have Down's syndrome are strong visual learners, they will be seeing what others in their peer group are doing and naturally they will want to do the same. If some of these things are overly ambitious, try to think creatively and look for similar achievable opportunities that might fulfil the same needs.

Self-esteem

Self-esteem is about our self-worth and feeling valued. Competence is one of the major building blocks of good self-esteem and another is being part of a community and having supportive friends and family who provide love and encouragement.

This will be a time when young people may start thinking about who they are and where they fit in to the world. If the subject hasn't been broached before, or recently, it is a good time to talk about Down's syndrome in an honest and straightforward way. It can really help people to develop a positive and realistic view of themselves to have an explanation for their experiences and feelings. Discussion about sameness and difference and talking about the person's strengths, talents, skills and the things they find more difficult can all help this process. In addition, it may be good to talk about a variety of people who have Down's syndrome, who the person knows, who are good role models.

It's really important to have friends who have Down's syndrome as well as other learning disabilities and also friendships with those who don't. We all need to feel we are not alone in the way we perceive the world and experience it. Friends who have Down's syndrome can be a great source of support and they will help the person to have a positive sense of shared identity.

Sex and relationships

Young people will need explicit and ongoing teaching at school and home about the changes they will experience during adolescence, healthy relationships, appropriate touch, rights, consent, sex, sexuality, gender, and contraception. This should include teaching about social skills and friendships covering such questions as: who are good friends? How do friends behave? Let the person you are supporting know they can come back to you with any questions they have.

Decision making and choice

Provide opportunities and support for making choices both big and small. We all want to feel we have choice and some control over our lives. Try to offer positive choices that minimise risk and the likelihood of failure. Remember to strike a balance, as too many choices all at once can be difficult for a person to cope with. Circles of support can help with making bigger life decisions and in supporting greater independence.

As young people grow up, it is important to have experiences (such as work experience in different settings) which will help them to make decisions about what they want to do. If someone has never experienced work, for example, they might really struggle to understand what "work" might involve.

Between the ages of 14 and 17 years, teenagers should have a child's needs assessment (also known as a transition assessment) from their local authority (social services). This will probably not happen automatically so it may be necessary to contact the local authority to request this assessment. The purpose of the assessment is to look at what the needs of the person are likely to be when they turn 18. The local authority should then give an indication as to whether the person is likely to have needs eligible for support at 18. The thinking behind this is that it should ensure that a young person is known to the local authority and may help with planning ahead for adult support and services.

Healthy lifestyle

Exercise can really help with teenage stress and it can promote positive self-esteem and good physical and mental health. Young people can exercise with their friends who have Down's syndrome and give each other support and encouragement. They can also get involved in sport and exercise opportunities in their local community. This can be a way of making new friends and being a part of the community. Embedding good habits in daily life can really stand the person in good stead when they leave home to become more independent.

Teenagers who have Down's syndrome who are 14 years old and over are entitled to a free annual health check with their GP.

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