Down's Syndrome Association
A Registered Charity No. 1061474

Emotional well-being

Supporting emotional well-being

For parents and supporters

A Down's Syndrome Association publication

Our Information Team is here to help

Please see our website for up-to-date information: www.downs-syndrome.org.uk
If you would like to talk about any of the issues covered in this resource, please get in touch with our helpline by calling 0333 1212 300 or by emailing us on info@downs-syndrome.org.uk.

Helpline Monday - Friday 10am-4pm | Telephone: 0333 1212 300

Acknowledgements

The DSA suite of 12 Supporting Emotional Wellbeing resources was designed, written and produced by Stuart Mills, Jane Mitchell and Geraldine White in consultation with Gillian Bird, Carol Boys, Rachel Fogden, Charlotte Knowles, Robin Gibson, Julian Hallett, Beth Medcalf, Christopher Osunsami, Kate Potter, Daniel White and, most importantly, 90 people who have Down's syndrome from all regions of England and Wales.

Emotional well-being is about how we think and feel and how we cope with life events. It is also about how we deal with our own emotions as well as those of others.

We have made a guide for supporters and parents to help you to think about ways to promote positive emotional well-being for people who have Down's syndrome. It contains lots of ideas and strategies, covering all aspects of life, as to how to prepare people for, and to support them when life is challenging.

However, as busy parents and supporters you will not always have the time or resources to put these suggestions into practice. Sometimes the person you support will experience poor emotional well-being even if you have done everything you can to support them.

It is important not to blame yourself in such situations.

You can contact the DSA for information and advice.

This resource contains details of health professionals who can help when a person is experiencing poor mental well-being.

Contents

An introduction to our emotional well-being resources for people who have Down's syndrome

The emotional well-being of parents, carers and supporters

- Self-kindness
- Mindfulness
- Some common mindfulness practices
- Support for carers
- Resources

Physical health and emotional well-being

- General health
- Getting help
- Sleep
- Resources

Learning about and recognising our emotions

- The function of emotions and emotional regulation (managing feelings)
- Recognising and naming feelings
- Making sense of feelings
- Taking control and managing feelings (emotional regulation)
- Stress bucket

Self Esteem and Self Identity

- Promoting self-esteem and developing a Positive self-identity
- Personal books and life story books
- Developing competence (focussing on what can be done)
- Having Down's syndrome and positive role models
- Pictures and sorting activities
- Resources

Independence, taking risks & choice

- Setting goals - learning new skills and tasks
- Visual and film guides
- Choice and making changes
- Making choices and changes – what helps
- Choice boards
- Circles of support
- Pictures and sorting activities
- What the law says about making decisions – The Mental Capacity Act (2005) (England & Wales) and Code of Practice
- Resources

Life Stresses & Strains

- Family & Relationship issues

- Life Stages
- Early childhood
- Adolescence/Teenage years
- Imagination and fantasy
- More serious issues/Trauma
- Adulthood
- Supporting people through times of change, loss and when things go wrong
- Paper and electronic visual timetables
- Social stories
- Self-talk
- Loss and what helps
- Loss of a friend who has moved away
- Loss of a support worker
- Loss of a sibling
- Loss of a classmate
- Resources

Difficulties & Coping Strategies

- Stress and anxiety
- What is stress?
- What is anxiety?
- Transitions
- What happens when we are anxious?
- Seeking professional help
- When does anxiety become a disorder?
- How can we help someone who has Down's syndrome when they are feeling anxious?
- How can we prevent anxiety?
- Strategies for helping a person who has Down's Syndrome to reduce stress and anxiety
- Anger
- What is anger?
- Dealing with anger
- Meltdowns
- Obsessive Compulsive Disorder (OCD)
- What is OCD?
- Sadness and feeling low
- Grief and bereavement
- Top ten tips for breaking bad news
- What helps
- Resources

Spirituality

- What is spirituality?
- How to support spirituality

Bibliography

An introduction to our accessible well-being resources

We have produced a suite of practical resources for people who have Down's syndrome, for use alongside this guidance, to support various aspects of emotional well-being.

Some people may be able to use some or all of these resources on their own, but others may need help from parents or supporters.

We have referred to these resources at various points in this guidance where we feel they will be helpful in supporting a particular aspect of well-being.

How am I? (easy read)

This is a teaching resource to help people identify their emotions, or feelings each day and to identify what might help them.

There are examples of emotions and feelings and blank sheets so that people can record their own.

There are examples of things that may help and blank sheets so that people can come up with their own ideas.

Most people will find it beneficial to work through the resource with a supporter, or teacher.

Let's talk about feelings (easy read)

This is a teaching resource to help people learn about emotions, or feelings. It covers:

- The words and signs we use to talk about feelings.
- What different emotions feel like?
- What different feelings look like on people's faces?
- What might make people feel different emotions?

Mindfulness (easy read)

This is a resource to help people understand what "Mindfulness" is and how they might bring mindfulness into their everyday life.

It includes links to a couple of mindfulness activities for people to try.

Stress Bucket (easy read)

This is a teaching resource to help people understand about getting stressed and good things they can do to help them to be calm again.

Things you can make or buy (easy read)

This is a resource about things you can make (or buy) to boost self-esteem and to help people feel better if they are feeling a bit low.

***Things I do to relax* (video)**

This video features people who have Down's syndrome talking about what helps them to relax.

***Relaxation activity* (audio)**

This is an audio recording to help people relax.

***Changes that can happen in families* (easy read)**

This is a teaching resource to help people to understand some of the changes that can happen in families. It offers reassurance that usually no one is to blame for these events and that they are a part of normal life for many families.

***Bullying* (easy read)**

This is a teaching resource to help people learn about different types of bullying and what to do if they are being bullied.

***Anger* (easy read)**

This is a teaching resource about anger; how anger feels and how to deal with it.

***Top ten tips for well-being* (easy read)**

The emotional well-being of parents, carers and supporters

This resource primarily focuses on how to support a person who has Down's syndrome. However, we wanted to start by acknowledging the importance of the emotional well-being of parents, carers and supporters. When we care for another person it is vital that we keep ourselves resourced and recognise our own needs. This isn't always easy and so this section gives more information and ideas about how to look after yourself and your own wellbeing.

Self-kindness

Be kind to yourself. If you don't look after yourself, it can make it harder to support someone else's emotional well-being.

How we relate to ourselves can have an effect on our emotional well-being. It is easy to feel good about ourselves when things are going well but life isn't always like that.

Everybody makes mistakes. We can't go through life without them. Often when we make mistakes, we beat ourselves up. We tell ourselves that we *'should have known or done better'* and we become our own worst critic.

We are allowed to make mistakes – we're not superhuman. Mistakes can help us to learn and make progress and criticising ourselves when we make a mistake doesn't achieve anything except to make us feel even worse than we already do. Self-kindness involves being tolerant of our mistakes and imperfections and talking to ourselves with a kind voice, perhaps how we would talk to a good friend if they were feeling bad.

Treating ourselves with kindness can help us to see where we went wrong, and to grow and improve from the mistakes we make.

Seeing others treat themselves kindly when things don't go well can help a person to learn this.

Mindfulness

Mindfulness means awareness and is about bringing our attention to our direct experience of life, moment to moment, rather than thinking about the past and future. This might be noticing sensations in the body, following the breath, eating, walking etc. When we notice our attention being pulled away by our thoughts, we acknowledge this and without judging we bring our attention gently back to this present moment.

A lot of our stress is caused by worrying thoughts, perhaps about something that has happened or something that we think might happen and when we have these thoughts, we might start to feel tense in the body setting off the natural stress response. We then might start to judge ourselves and add more tension. This can happen without us being conscious of it.

Mindfulness helps us to become more aware of our experience and to get out of what is called autopilot, allowing us to make choices in how we respond in life rather than reacting.

Breathing meditations help to activate what is called our Parasympathetic Nervous System which is also known as the "rest and digest" system. This is the opposite of our Fight, Flight, Freeze response (Sympathetic Nervous System). As we take our attention to the breath and it naturally start to slow and deepen, we calm the mind and body.

Some Common Mindfulness practices

A **Body Scan** is when we move our attention around the body starting with either the head or the feet and noticing the sensations.

A **Breathing Meditation** is when we take the attention to the breath feeling the sensations of each in and out breath either moving through the body or at a particular focussed point.

Walking Meditation is about bringing our awareness of the physical sensations in our body as we move, really feeling the sensations in the feet and being present with our experience of moving. It usually involves slowing down, pausing and having a greater awareness of what is around us.

Mindful Movement is when we bring Mindfulness to movement. That is the intention to be present with the sensations of the movement rather than focusing on the outcome.

We can also bring Mindfulness into our everyday activities and here are a few suggestions:

- Having a shower - feeling the sensations of the water on our skin rather than thinking about everything we have to do when we get out
- Washing up – feeling the warm water on our hands
- Eating a meal – really smelling and tasting each mouthful
- Watching a film – giving all our attention rather than simultaneously texting and browsing the internet
- Listening – giving someone our full attention when they are talking rather than planning what we are going to say or attending to other things

If you are interested in learning more about Mindfulness you could attend a taster session or a course. There are also online courses, apps and books available. If you are wanting to attend a group or session check the teacher is listed by BAMBA (British Association of Mindfulness-Based Approaches).

Support for carers

Parent carers tells us they find support from other parents, who may share similar experiences, to be of great value. As a result of this feedback, the DSA has set up a number of closed Facebook Groups for parents covering all age ranges and a number of specific subject areas (including complex needs/autism and dementia). The groups may be accessed via the Down's Syndrome Association Facebook page.

In addition, there are local parent support groups that are affiliated to the DSA, throughout England, Wales and Northern Ireland. Please check our website for information about support groups or you can contact us for further details.

Local carers organisations (not specific to those who are caring for a person who has Down's syndrome) exist throughout the country. The organisation 'CarersUK' has a *'Support where you live'* search facility at their website.

Unpaid carers of children, young people and adults who have Down's syndrome are entitled to ask their local authority for a carer's assessment of their needs. The DSA website provides detailed information about carer's assessment and our Information Officers can help if you have any questions about carers assessments.

Contact the DSA

If you have any questions about the issues covered in this section, you can call DSA's Helpline (Tel: 0333 1212 300) or email using **info@downs-syndrome.org.uk**

Physical health and emotional well-being

General health

It is always important to think about the whole person. If physical health is not good, this may affect emotional well-being.

It is vital that people who have Down's syndrome are supported by their families and supporters to access good healthcare as and when they need it.

People who have Down's syndrome may have difficulties telling you about their pain/illness and where it hurts. Pain may not be understood, or communicated as pain, but as another feeling such as discomfort or worry. There is some evidence to suggest people who have Down's syndrome may be more sensitive to pain but that it takes a while for people to express (in whatever way) how they are feeling.

Those around the person may have to look for non-verbal clues that indicate they are unwell or feeling uncomfortable (for example: changes in mood, routine, appetite and behaviour). If the person you support is feeling unwell or in pain, but they find it hard to express this, they might feel upset, anxious or have low moods.

Some people will benefit from having the chance to practice/role-play with resources which will help them to indicate pain or discomfort without necessarily using the spoken word. Various examples may be found on the internet. These may feature different parts of the body, for example, with a caption 'The pain is in my……'. You may like to use the resources you find as a basis to make your own tailored resource to best meet the needs of the person you are supporting.

Behaviour changes in women who have Down's syndrome may sometimes be associated with menstruation. Some women will experience premenstrual syndrome, and some will experience painful periods (dysmenorrhea). As with women in the general population, women who have Down's syndrome will experience the menopause although the average age of onset is earlier (around 42 years rather than 51 years)

Getting help

GP

If the person you support has any health issues, you should make an appointment with the GP or (where appropriate) seek emergency advice.

Anyone who has Down's syndrome, and who is aged 14 years and over, is entitled to a free annual health check with their GP. There is information about annual health checks at our website.

Annual health checks do not replace the need for other health screening (for example: testicular, breast and cervical) and general GP appointments/check-ups as and when needed.

Community Learning Disability Team (CLDT)

CLDTs have been set up to serve the particular health needs of adults who have learning disabilities. CLDTs vary in size and make-up but typically they will contain community learning disability nurses, a psychologist and a psychiatrist. Your GP can make a referral to the CLDT on your behalf. Some CLDTs also take direct referrals from people who have learning disabilities, their families or paid supporters. You can find your local CLDT by searching online; the details are usually to be found on your local NHS Trust website.

Child and Adolescent Mental Health Services (CAMHS)

CAMHS are the NHS services that assess and treat young people with emotional, behavioural and/or mental health difficulties.

You can find your local service by searching online; the details are usually to be found on your local NHS Trust website.

Sleep

Sleep issues are more common in people who have Down's syndrome.

Seek help if you think the person you support has sleep issues

Like all of us, people who have Down's syndrome need a good night's sleep to be able to function properly. We know that sleep issues are common in children and adults who have Down's syndrome. The causes for sleep issues may be behavioural, physical (for example, due to sleep apnoea) or a mixture of both.

A person who has Down's syndrome may not realize, or be able to tell you, they are suffering from poor or disturbed sleep. Therefore, as a parent or supporter, it is good to be aware of some of the signs that may indicate a person has sleep issues. These can include irritability, anxiety, over activity, aggression, impaired attention and daytime sleepiness.

It is important to stress that poor sleep is not an inevitable part of having Down's syndrome and it is potentially treatable. Assessment and treatment of sleep issues should be available to everyone who has Down's syndrome to help improve quality of life.

It is important that you seek help from the GP if you think the person you support is experiencing sleep issues. If appropriate, they will make a referral to a specialist sleep service.

DSA Resources

The DSA has free resources to support good health free to download from our website:

- ***Healthy eating and exercise* (easy read)**
- ***Staying healthy* (easy read)**
- ***Going to the doctor* (easy read)**
- ***Going to the chemist* (easy read)**
- ***Managing sleep issues in children***
- ***Sleep issues in adults***

Health Swap: The Health Living App
https://www.dsactive.org.uk/healthy-living/11991-2/
This App has been designed to help people who have Down's syndrome and their parents or supporters to make positive changes to their lifestyle through healthier eating and activity tracking, whilst also improving their digital skills and capabilities.

Contact the DSA

If you have any questions about the issues covered in this section, you can call DSA's Helpline (Tel: 0333 1212 300) or email using **info@downs-syndrome.org.uk**

If an information officer is unable to answer your question, they can make a referral to the medical adviser at the UK Down Syndrome Medical Interest Group (DSMIG). Please note DSMIG can provide general advice about health issues but they are not able to comment on individual test results. DSMIG are happy to take enquiries from health professionals but they will not take direct from enquiries from families or supporters.

Learning about and recognising our emotions

People who have Down's syndrome are likely to need extra help to learn about feelings and emotions and how to cope with them in positive ways.

DSA well-being resources for people who have Down's syndrome to support teaching around emotional recognition and emotional regulation (managing feelings):

- ***How am I? (easy read)***
- ***Let's talk about feelings (easy read)***
- ***Anger***
- ***Stress Bucket (easy read)***
- ***Mindfulness***
- ***Things I do to relax (video)***
- ***Relaxation activity (audio)***

The function of emotions and emotional regulation (managing feelings)

Emotions, or feelings, are part of being human. They are experiences which affect our bodies, our thoughts and our behaviour.

Emotions can be helpful or unhelpful. At a basic level, they are important for survival. They help us tune in to things like pleasure, attraction and danger.

Emotions are affected by physical, neurological (the brain), social, environmental factors and experiences.

Part of development involves learning to express and to manage our own and others' emotions. This is sometimes called emotional regulation. Babies cannot do this at all, and toddlers are not much better! However, children can start to learn to recognise and name feelings (their own, and other people's) and to be able to have some self-control from quite an early age though these abilities continue to develop through adolescence into adulthood.

People who have learning disabilities will experience the same feelings and emotions as anyone else; they may struggle, though, to express how they are feeling, and to understand and manage their own emotions, and those of others. This includes so called negative emotions such as anxiety, sadness and anger. People who have Down's syndrome will have such feelings but can feel under pressure to be 'happy' all the time.

People who have learning disabilities, including people who have Down's syndrome, are likely to need extra help to learn about feelings and emotions and how to cope with them in positive ways

We can think about 6 steps towards recognising and managing emotions and feelings

1. Recognising feelings
2. Naming feelings
3. Making sense of feelings
4. Taking control of feelings
5. Trying different ways to manage feelings
6. Developing a coping strategy
   (e.g. stress management, anger management, coping with sadness and low mood)

Recognising and naming feelings

Label feelings in the person who has Down's syndrome (e.g. *'you look happy'* or *'I think you are feeling a bit sad today'*). It can also be a good idea to label emotions as portrayed on TV and in films. Depending on the level of understanding of the person who has Down's syndrome, TV shows such as soap operas can provide lots of examples of feelings and people dealing with them. However, be aware that one of the characteristics of people who have Down's syndrome is that they can sometimes be rather sensitive to other people's feelings and may find it hard to separate their own experience from that which they are observing.

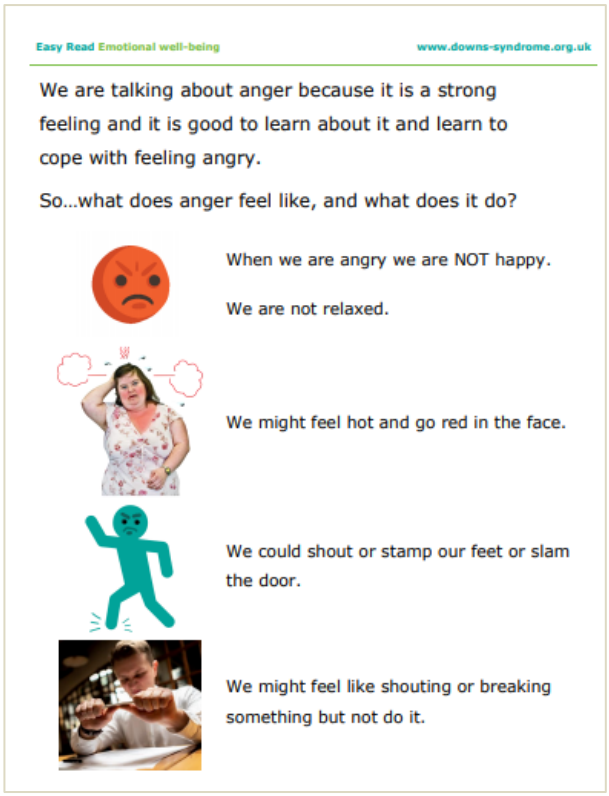
It is good to help the person develop a vocabulary to describe and express feelings. How extensive this is will depend on the person and their level of cognitive and language development. Some people are only able to distinguish simple emotions such as happy, sad or scared whereas others will be able to understand such feelings as surprised, confused, frustrated …etc. Also, bear in mind that some people who have Down's syndrome can use vocabulary, or repeat things they have heard, without truly understanding the meaning of what they are saying. It's always worth just gently probing and checking out what the person's understanding is and looking for other signs that might help you interpret what they are trying to tell you (e.g. body language, behaviour).

Making sense of feelings

To make sense of our own and other's feelings, it helps to learn about how emotions affect our bodies, our behaviour and even our thoughts.

Also, we need to learn about our own emotional reactions…what makes us feel a certain way, what triggers our feelings of sadness or anxiety for example, as well as what can make us feel calm, settled and relaxed. This is known as **emotional literacy** and is the first step towards being able to manage and cope with feelings, known as **emotional regulation.**

We know that many people who have Down's syndrome, although they can feel things quite intensely and pick up on other people's emotional states, may not easily express their emotions, and to understand and process their own emotional experiences as well as those of other people. So, providing support and teaching in this area is just as important as teaching reading, maths or making a meal, for example.



Easy Read Emotional well-being www.downs-syndrome.org.uk

We are talking about anger because it is a strong feeling and it is good to learn about it and learn to cope with feeling angry.

So...what does anger feel like, and what does it do?

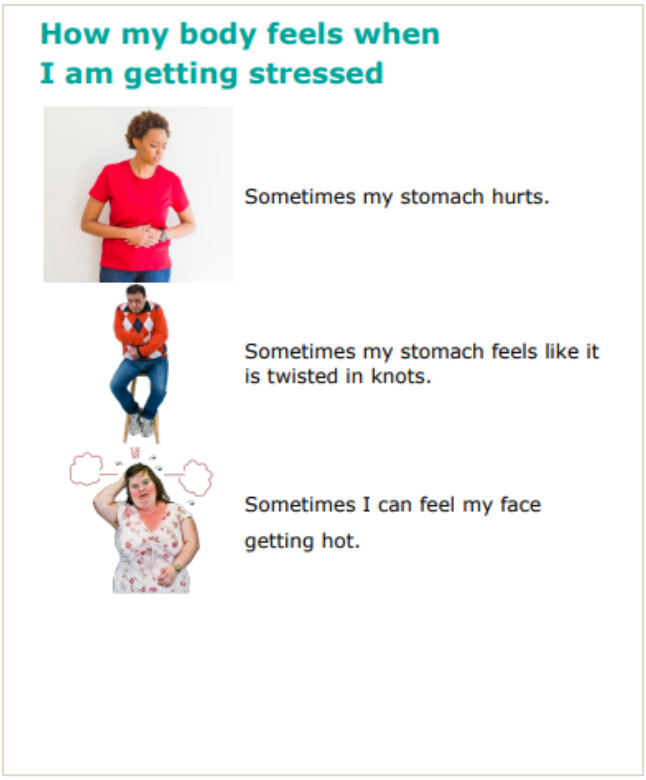
When we are angry we are NOT happy.

We are not relaxed.

We might feel hot and go red in the face.

We could shout or stamp our feet or slam the door.

We might feel like shouting or breaking something but not do it.



How my body feels when I am getting stressed

Sometimes my stomach hurts.

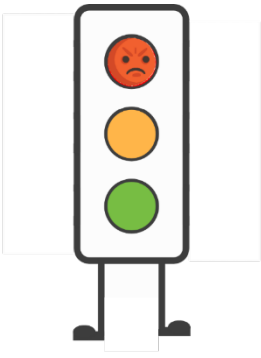
Sometimes my stomach feels like it is twisted in knots.

Sometimes I can feel my face getting hot.

Taking control and managing feelings (emotional regulation)

Learning emotional self-control and how to cope with feelings, both positive ones and difficult ones, is part of every child's process of cognitive, social and emotional development. Young children have little or no emotional control - think of the average toddler – anger/excitement and frustration are expressed first and foremost through behaviour and we accept that this is a stage that children go through as they don't yet have the concepts or skills to act differently.

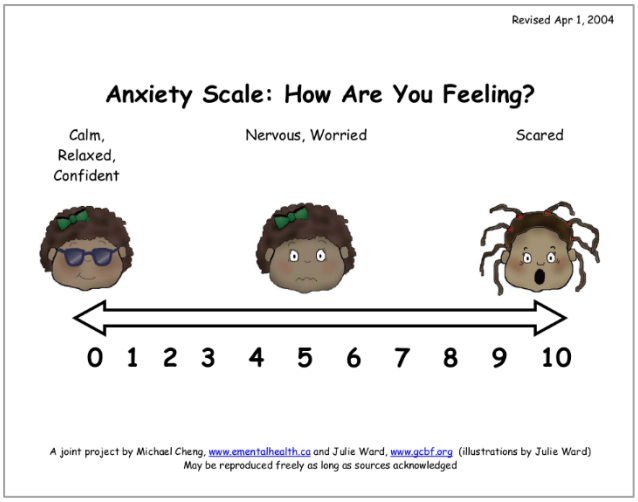
Lots of resources for children and people with additional needs use different images and metaphors (e.g. volcanos, thermometers, traffic lights) to represent the process of emotional arousal and to illustrate when emotions get out of control. The extent to which these ideas make sense to a person who has Down's syndrome will depend on that individual. Traffic light type systems are likely to be helpful for many and can be backed up by colours and visuals. However, the best thing is probably to develop personalised rating scales using the child or adult's own language (based on emotional literacy work) and photos, cartoons or drawings that make sense to them.

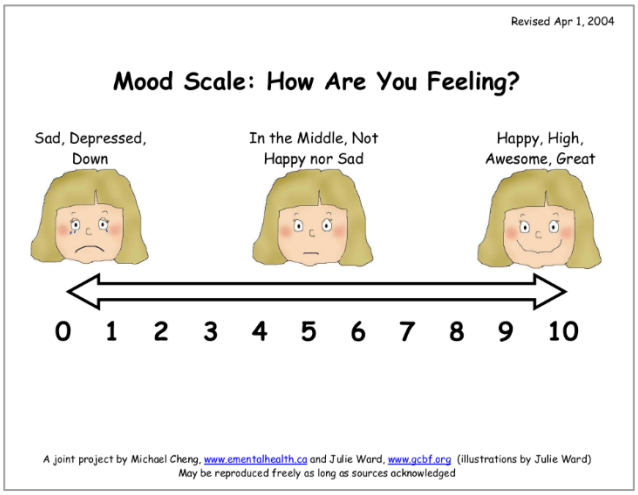


Also remember that *'getting stressed out'* or *'having a meltdown'* can mean very different things to different people so will need exploring to understand what they actually mean, what they look like, and feel like.

It is important to reassure people that emotions like sadness, anger and fear are all perfectly normal and part of being a human being. The simple message is *'it's OK to be angry but not OK to hit people.'*

Working on coping and self-soothing strategies helps people to become aware of, and be more in control of, their emotional arousal.





Another helpful way to think about emotional control and regulation is to think in terms of energy management, or *'balancing the energy books.'* We all find that certain situations, or physical issues like tiredness or feeling hungry, make us more *'emotional'* and we find it harder to cope with stress or worry and stay calm and focussed at these times. Other things such as watching a funny film, going for a walk, yoga, massage or talking to a friend help us feel more capable and able to take things in our stride.

We can think about a battery and the things which drain the energy from us and the things that help us to recharge. These are sometimes referred to as Sustainers and Drainers and we need to try and get a balance between the two.

Sustainers	Drainers
All the things that give you pleasure, energy or calm.	All the things that use up your energy, make you feel drained.

The stress bucket

Another way of thinking about energy balance in stress and coping is to think about a bucket. All the things that cause anxiety or stress, or that the person finds difficult to cope with can fill up the bucket. One small thing (for example: a demand, sensory overload, a difficult task, not being able to communicate or understand) can then lead to the bucket getting full and overflowing. This is when the emotional brain takes over from the thinking brain and *'fight or flight'* response can kick in.

So, in this analogy, you can punch holes in the bucket using sustaining or coping strategies (for example: sleep. relaxation, looking at a social story). There is information about social stories in the **'Life stresses and strains'** section of this resource.

What fills your stress bucket?

What helps to punch holes in your bucket so that the stressful feelings reduce?

What helps your family member/person who has Down's syndrome?

You can access our **stress bucket** resource through our website.

Self-esteem and self-identity

Self-esteem is about our self-worth and feeling valued. Having a happy and loving upbringing with consistent care and support will really help to foster and strengthen good self-esteem and self-identity.

DSA well-being resources for people who have Down's syndrome to support self-esteem:

- ***Things you can make (or buy)***
- ***Mindfulness***

Promoting self-esteem and developing a positive self-identity

Being part of a community and having good friends and family who provide love and encouragement are all building blocks that support good self-esteem. It is important to have friends who have Down's syndrome as well as other learning disabilities and 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 comradeship and they will help the person you support to have a positive sense of shared identity.

People who have Down's syndrome tell us the following things are important in their daily lives:

- **family, friends and relationships**
- **good support**
- **making choices about what we want to do with our lives**
- **having a job**
- **having a social life**
- **being listened to**

All of these things, in combination and according to individual preference, support mental well-being and boost self-esteem.

Many people who have Down's syndrome benefit from support to develop and maintain 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. This is more likely to be the case for people with complex needs who may not be interested in or may be less able to manage friendships and social relationships. You could think about setting up a Circle of Support (sometimes also known as a Circle of Friends). There is further information about Circles in the **'Independence, taking risks & choice'** section of this resource.

Personal books and life story books

'All about me' personal books containing photos of happy life events, family, friends and reminders of achievements, can be a tool to help boost self-esteem and they can help support communication. They can also be used as a shared activity (if the person is happy to share) and a conversation starter particularly with new friends or support workers. Personal books can be created quite easily on a phone, PC or tablet. Alternatively, photos/pictures stuck on to paper with handwritten titles can work just as well.

For example, a photo like the one on the right could be included in a personal book with the title *'having fun with my sister'*

Life story books can help to support good self-esteem and also to explore identity. The focus and purpose of life story books may be slightly different to personal books. They are accounts of a person's life that can include stories and memories of life events and relationships; the things that make us who we are.

As with personal books, these can be created on a phone, PC or tablet or made by hand.

Helen Hewitt, the author of a resource about life story books for people with learning disabilities, writes:

'Identity is what makes us unique. People with learning disabilities are often denied the opportunity to consider who they are and how life events affect their identity. This is even more pertinent in the light of current community care where people are faced with many transitions in their lives which can lead to a lack of continuity, and even a loss of identity, if a person's past experiences are not acknowledged……

In addition to helping the person with learning disabilities, these books also enable others to see beyond the 'client' identity and appreciate that each person has a unique life history that sets them apart from other people.'

Developing competence (focussing on what can be done)

Developing competence is another way of supporting good self-esteem. We all want to do things for ourselves where we can. To do so gives us a greater sense of independence and control over our daily lives and enhances feelings of pride and self-esteem. Developing competence is about focussing on what can be done, emphasising a person's unique strengths, interests and skills and building on them gradually over time. At home, this process starts in the early years and continues with supporting the person to learn and practise self-care skills and then daily living skills.

Every step a person takes is valuable. As they grow up, some people will be able to learn more advanced daily living skills such as clearing/laying the table, unloading the

dishwasher, dressing, helping others, having responsibilities with, and for, other people, family pets, tasks. For others, learning to pull up the duvet to make the bed, putting rubbish in the bin and/or laundry in the laundry basket will be a huge achievement. It is so important to value people for whatever they can do, be it at home, at school or in the community. Remember to thank people for what they do and praise them for their achievements.

Having Down's syndrome and positive role models

As is common for people everywhere, some people who have Down's syndrome may have thoughts about who they are and where they fit in to the world. This will often happen during the teenage years and early adulthood. You may have had a discussion, or discussions, about Down's syndrome and what it means as the person was growing up. It is good to think about whether it is time for refreshing and revisiting the subject. If possible, take the person's lead if they begin to ask questions.

It is never too late to have this discussion. Some people may not have had their condition explained to them and so spent time worrying about it. Talking with the person you support about their condition in an honest and straightforward way may provide them with an explanation for their experiences and feelings. It may also help them to develop a positive and realistic view of themselves. 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. Many DSA resources can be used to talk about Down's syndrome. There are an increasing number of films and TV programmes featuring actors who have Down's syndrome. Parents and supporters will need to use their judgement as to which might be meaningful and helpful to the individual who has Down's syndrome in terms of reinforcing a positive self-identity.

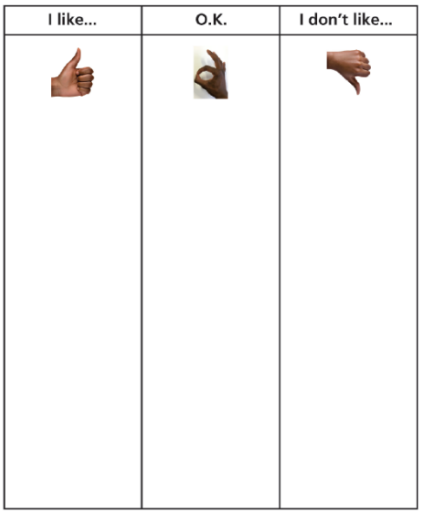
Pictures and sorting activities

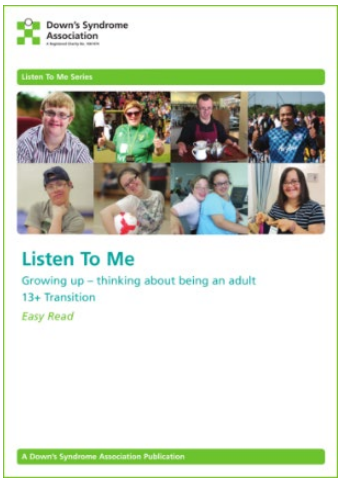
Using photos with matching and sorting activities can be a useful tool to help some people explore their sense of identity. Pictures, photos and symbols can be paired with words and sentences to explore a topic. You can make a personal sorting board with two or three columns to explore any topic. A visual sorting board and manipulatives (photos, pictures, words, symbols) give people time and space to think about information, work out what it means, and give their view/make choices. For the purposes of exploring sense of identity you could use:

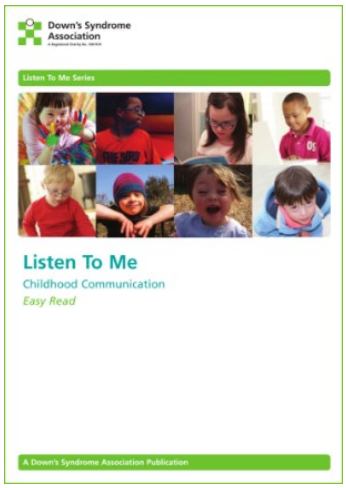
- a picture of a person who has Down's syndrome and a picture of a person who does not have Down's syndrome
- a picture of the person you support and a picture of their sibling – *'me'* and *'my sister'*

A speech and language therapist or a learning disability practitioner can offer advice about how to use sorting activities.

Examples of sorting formats are provided in our *Listen To Me* resources available on our website.







Balance

Of course, there is a balance to be struck; Down's syndrome is only a part of the person. The ideal is to nurture good self-esteem so the person you support is able to have an understanding and acceptance of who they are as a valued individual who happens to have Down's syndrome. Each person who has Down's syndrome is different; some people will not think about, understand, or worry about their condition. Some people may go through a stage where they are unhappy about having Down's syndrome.

If the person you support has a negative view about themselves as a person who has Down's syndrome we would suggest seeking outside advice. This may be from the DSA, your local Child and Adolescent Mental Health Services (CAMHS) or the Community Learning Disability Team (CLDT) as appropriate.

DSA resources to support discussion about Down's syndrome

These resources contain many positive life stories that may be helpful when discussing Down's syndrome

- ***Our life stories*:**
- ***Celebrating our lives – Adults with Down's syndrome***
- ***Down2Earth Magazine***

Other resources

West Sussex County Council & Sussex Partnership NHS Foundation Trust

Promoting emotional resilience:
https://hbtg.org.uk/wp-content/uploads/2015/06/KAN-Emotional-resilience-toolkit.pdf

Contact the DSA

If you have any questions about the issues covered in this section, you can call DSA's Helpline (Tel: 0333 1212 300) or email using **info@downs-syndrome.org.uk**

Independence, taking risks and choice

Setting goals - learning new skills and tasks

Teenagers and young adults who have Down's syndrome will be seeing what others in their peer group are doing and naturally, they will want to do the same. Sometimes the desire to do something for self may be reasonable and achievable but at other times it may throw up difficulties and worries about the person's safety.

Being able to communicate our needs, wishes and dreams and have them heard and understood is important for our sense of identity and our well-being. People who have Down's syndrome can become frustrated and unhappy after having tried unsuccessfully to let those around them know their needs or opinions. In some cases, they may not have been listened to or, if they were, their needs/views were not taken seriously. If this has been a common experience for people, they may understandably just give up and be less likely to try or give things a go in future. This is sometimes referred to as *'learned helplessness'.*

To try to avoid this happening, the person you support needs to know they will be heard and that they can make positive changes in their lives. The environment around the person should be sensitive and responsive to their needs. You may see that the person wants to have a go at something they haven't done before. If it is safe to do so, let them have a try. If needed, show them what to do and give them lots of chance for practice. Give prompts if necessary and lots of praise. Sometimes, people may surprise you in that they have quietly watched you do a task over time and now they are ready to do it themselves successfully.

Spend time to sit down with the person to explore what new skills/tasks they want to achieve in the future so you can set goals together. Finding out what the person wants may take time; ask questions, listen, watch and ask them to show you what they would like to do. Check back with them that you have understand what they are trying to tell you.

Remember that visual resources are helpful for people who have Down's syndrome. Use pictures, photos and/or drawings when planning goals. Where the person is unable, or finds it hard, to explain what it is they want to achieve, there may be an element of trial and error where you use what you already know about them to try to work out what it is they want to do.

Visual and film guides

Visual and film guides

Visual guides can support success and independence. They can also help prepare a person for new experiences. They can help people express and share their thoughts and feelings.

Visual guides can also be made as short films. The person the guide is for can act in the film and in photographs for their personal books.

Visual guides might show:

- A sequence of events in a situation
- Who will be there
- How people are likely to behave
- What to do if a person feels worried, unwell or if unexpected things happen.

Visual guides can help people:

- understand situations
- understand language (e.g. go, now, finish, next, first, and then, last, end, tenses
- choose
- self-monitor.

How to make a visual guide

You can make your own books or use apps/programs to help create visual guides, personal books and films. Using suitable ICT, you can also record voice descriptions.

Use real photos or symbolic pictures – there are many symbolic picture systems available.

Edit your films to get the best clips for a short film.

Write sentences that describe the photos and film clips in positive language

Some things to think about when planning and working towards goals:

- What is the person physically and developmentally ready to do?
- If a dream/wish/goal is overly ambitious, try to think creatively and look for similar achievable opportunities that might fulfil the same needs.
- Keep it simple by setting easy to understand and specific measurable goals – this way you know when you get there!
- Don’t pile on the pressure as this will cause stress and worry – set one or two achievable goals rather than lots at the same time.

- Create opportunities where the person can take on some responsibility and/or is able to help others.
- Break goals into small achievable steps where necessary.
- Re-visit and reassess goals – are any tweaks necessary (for example: change in pace or further breaking down of goals into smaller steps)?
- Visual progress charts and prompts may be useful.
- Create opportunities for the person to practise their new skill(s) in different contexts and environments.
- Praise is very important.

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, people who have Down's syndrome need to be able to learn as a result of trial and error and by making mistakes. You will need to think about how you deal with such situations so that people are only exposed to manageable levels of frustration that don't put them off achieving their goal.

As part of the goal setting process you may be thinking about possible risks for the person you support. Thinking about risk does not just have to be about focusing on the 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 on the bus 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.

Inevitably, there will be times when mistakes are made, and things will go wrong. This is OK and to be expected; making mistakes is part of daily life for everyone.

Social stories can be a useful tool to:

- help people to understand that it is OK to make mistakes or get something wrong.
- help people to understand what to do when a mistake is made and/or when things go wrong.

There is further information about social stories in the **'Life stresses and strains'** section of this resource.

Achievement will be different for each person; a small step for one person might be a very big step for another!

Choice and making changes

Making meaningful choices helps us to feel valued and increases our confidence and self-esteem. A lack of choice and control over our daily lives can lead to frustration and have an adverse effect on our emotional and mental health.

From an early age give children choices; this could be choosing a toy, a game, an item of clothing, a bedtime story or a choice of snacks. Without intending to, it can be easy to forget to provide choices particularly when you are a busy parent. However, it only takes a minute to offer a choice and wait for your child to point or look at the chosen item and/or say which they would prefer. An activity box containing a range of things that your child enjoys is a good way of encouraging choice. It is also a useful tool to have when your child needs a change of activity or maybe time out.

'Giving a choice, one you know that your child will like and one less popular, will help to encourage communication. Show the child the objects that they can choose between (using pointing, gesture, signing and/or words). Then give the child time to see if he or she will choose independently.

- ***'Do you want to look at X book or Y book?'***
- ***'Would you like juice or milk?'***

It is important to give your child the one they choose, even if you feel they haven't fully understood the question.

Later on you can ask your child more open-ended questions, for example:

- ***'What would you like to drink?'***
- ***'Which toy do you want?'***

Source: DSA resource- *Encouraging communication for children*

Life is a balance and we cannot always have what we want when we want it. So, your child will need to learn about choice alongside other skills such as waiting and the need to finish a task (for example: *'If you do this now then you can do this', 'We will do this one now and then this one').*

Some teenagers and adults may not realise, or understand, they have choices or that they can change things in their lives. So, where possible, help the person you support to make choices and to have an understanding of the things they can change in their lives.

Making choices and changes – what helps

Here are some of things people who have Down's syndrome tell us are helpful or unhelpful to them when they are making choices:

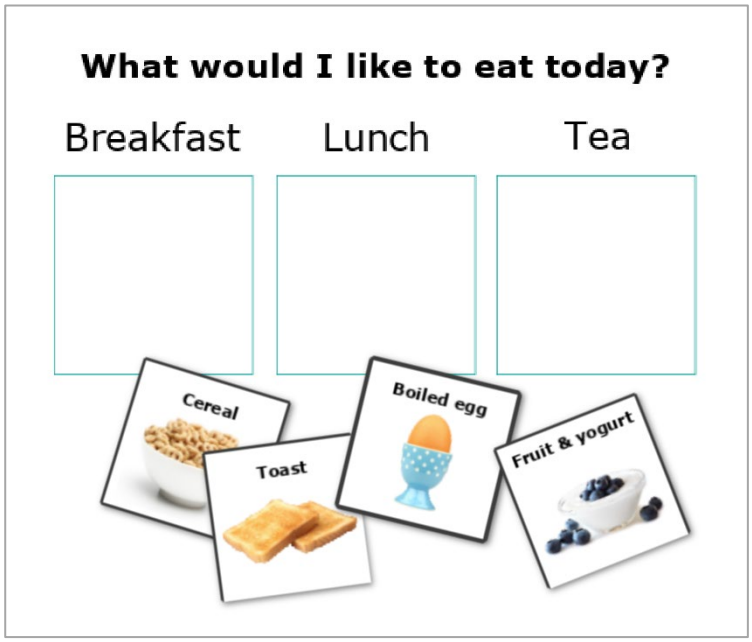
Helpful

- ***To have someone to talk with***
- ***Talking to parents, friends, family, and support workers***
- ***Using an advocate***
- ***Circle of support***
- ***Hearing what other people think***
- ***Pictures and words – a bit of both***
- ***Doing things at my own speed***
- ***I like it when someone says "That's a good decision"***

Unhelpful

- ***Too many choices at once***
- ***Being rushed as it is stressful***
- ***People being bossy***

Provide opportunities, practice and support for making choices both big and small. Try to offer positive choices (where possible) that minimize risk and the likelihood of failure. Remember to strike a balance, too many choices all at once may be difficult for people to cope with.



Choice boards

Choice boards can help support choice making in a simple visual way with photos/pictures representing the choice the person has to make.

For example, the board could contain photos of a selection of activities to choose from or two photos of snacks.

Circles of support

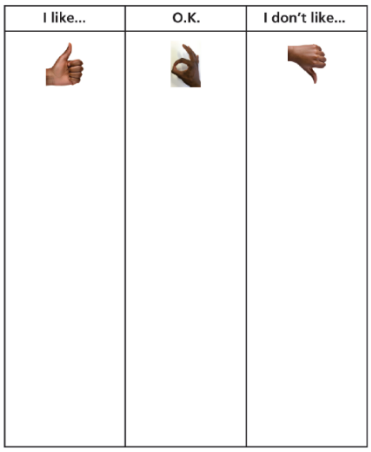
Circles of Support can help with making bigger life decisions and in supporting greater independence. A circle of support is a group of people who know a person well, such as family, friends and supporters, who meet regularly to help the person they support achieve what they want. This can include sharing 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. There is no formal process to setting up a circle of support and you can organise it yourself.

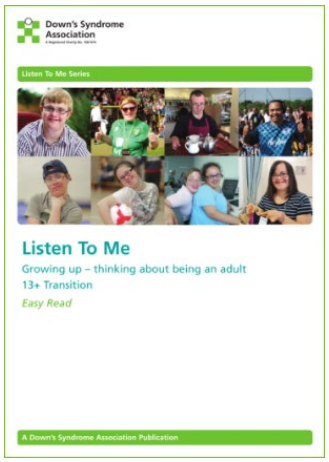
Pictures and sorting activities

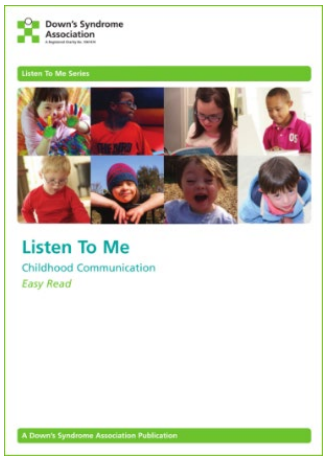
Using pictures/words in sorting activities can help people to think about and communicate their choices. You can make a personal sorting board with two or three columns to explore any topic. A visual sorting board and manipulatives (photos, pictures, words, symbols) give people time and space to think about information, work out what it means, and give their view/make choices.

A speech and language therapist or a learning disability practitioner can offer advice about suitable visual sorting activities and how to use them.

Examples of sorting formats are provided in our ***Listen To Me*** resources available on our website.







People who have Down's syndrome learn well by seeing, doing and having real experiences. If someone asked you if you want to do something and you have no idea what *'something'* may involve because you have never done it before, it is probably safer for you to say no! Therefore, it is important to support people to have new experiences which will help them to make decisions about what they want to do.

Here are some examples:

- Work experience
  Organise a variety of experiences in different settings. If someone has never experienced *'work'* before, they might not understand what *'work'* might involve.

- Choosing where to live
  If there is a choice between two places, take the person to visit both options so they

can make a proper informed choice based on what they have actually seen and experienced.

There may be situations where it is not possible to visit a place or experience something before making a choice (for example: going on holiday somewhere new or choosing to be a bridesmaid at your brother's wedding). In such situations, you can still take steps to help the person to make a choice.

Film clips and/or photo stories can help by:

- showing what the event or activity might be like
- showing the person what they will need to do

People may make decisions you think are unwise, but they should be allowed to do so if they have capacity.

It is very natural as a parent or supporter to feel protective. Sometimes you may have to resist the temptation to step in to try and stop the person you support from making a decision with which you disagree.

You may find the person you support makes decisions about life partners, leaving home, their identity and sexual orientation which conflict with your views and beliefs.

This is a normal part of the process of growing up, being an adult and learning about life and the impact of our decisions.

What the law says about making decisions – The Mental Capacity Act (2005) (England & Wales) and Code of Practice

It is important for families to understand the legal framework around decision making for young people in England and Wales once they turn 16. It can come as a surprise to parents to discover that they do not have an automatic right to make decisions for their older teenagers and adult sons and daughters who have Down's syndrome.

The relevant law is the Mental Capacity Act (MCA) 2005. The Act provides a common sense approach to supporting people in making their own decisions when they are able and to protecting their interests if they can't make specific decisions for themselves. The MCA Code of Practice provides guidance for decisions made under the Act. There are links below to DSA information about the MCA and to the MCA Code of Practice.

DSA resources for supporting choice and independence

- ***Listen to Me – Childhood Communication (easy read)***
- ***Listen to me – Growing up and thinking about being an adult (easy read)***
- ***Making every day financial, health and welfare decisions post 16 years***
- ***Why is being heard and included in decision making processes important?***
- ***Learning to be independent*** **(easy read)**
- ***Making choices*** **(easy read)**

Other resources

Office of the Public Guardian

Mental Capacity Act 2005 and Code of Practice

https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice

Contact the DSA

If you have any questions about the issues covered in this section, you can call DSA's Helpline (Tel: 0333 1212 300) or email using **info@downs-syndrome.org.uk**

Life stresses and strains

Everyone is an individual but there are some common issues and challenges as a child who has Down's syndrome grows up which can affect their emotional development.

DSA well-being resources for people who have Down's syndrome relevant to life stresses and strains

- ***Changes that can happen in families***
- ***Anger***
- ***Stress Bucket***
- ***How am I?***
- ***Let's talk about feelings***
- ***Bullying***
- ***Mindfulness***
- ***Things I do to relax (video)***
- ***Relaxation activity (audio)***

Family and relationship issues

Nearly everyone who has Down's syndrome grows up within a family (this was not always the case in the past)

Families are different from each other in terms of who is in them and the way they function. Families include parent/s and sometimes siblings but also wider extended families including grandparents, aunties and uncles, cousins, stepparents and step/half siblings. Most people who have Down's syndrome develop close and loving relationships with family members and like to be an important part of family life. People within the family network can react in different ways to the arrival of a child who has Down's syndrome and have different ideas as to how to support them. This can be a source of tension within families. Often the wider family provides the basis and support for a person who has Down's syndrome to develop into a well-functioning individual.

Early in a child's life, the family and, in particular, the parents or primary caregivers, provide the child with the basis for healthy emotional development. This is based on a concept called attachment and leads to what psychologists have called a *'secure base'.*

Secure attachments come from the child having their needs recognised and met reasonably, consistently and predictably by their parent. Initially these needs are for food, warmth, comfort and safety. Later on children need their parents to allow them to explore and take some risks, express their feelings (both positive and negative), and to cope positively with difficulties like the child becoming anxious, angry or upset, being ill/in pain, making mistakes, misbehaving and having accidents.

Some things that can affect or disrupt the secure base include:

- Childhood illness, especially if it involves hospitalisations and/or separation from parents. This makes both parent and child anxious and can put a big strain on family life.
- Poor mental health of parent
- Marital discord/breakdown
- Domestic violence
- Parental drug/alcohol misuse
- Homelessness/frequent changes of home and school.
- Need for fostering or adoption

This is not to say that if these things happen, because they do sometimes and cannot be avoided, that the child will definitely become insecure and have poor emotional development and well-being. However, they may be more at risk and will need more care and understanding of their behaviour if these events have affected them. Having a learning disability and communication difficulties can make it harder for children to express their needs and feelings. However, most parents learn to *"read"* their children who have Down's syndrome very well, even when they are not able to communicate verbally. These DSA emotional well-being resources can be used to help people to express how they feel:

- ***Anger***
- ***Stress bucket***
- ***How am I?***
- ***Let's talk about feelings***

No one can be a perfect parent!

Children who have learning disabilities, including those who have Down's syndrome, can present particular challenges for parents/families from time to time. This can be for many reasons including: accepting and adjusting to diagnoses and disabilities, extra pressure from health appointments, dealing with the "system" (education, social care, health etc), financial issues, dealing with challenging behaviour, worries about siblings and/or worries about the future. If a child has more complex needs such as a dual diagnosis, sensory impairments and/or chronic illness, this will impact upon family and parental emotional wellbeing/stress so maybe even more important to get support and look after yourself. Please see the **'The emotional well-being of parents, carers and supporters'** section of this resource for further information. If you are experiencing any of these issues, you can contact the DSA and we will do our best to help.

Most families will be able to manage the ups and downs and the young person who has Down's syndrome will grow up feeling generally safe and happy and develop a positive self-identity and confidence to try new things.

Life Stages

There are some common issues and challenges as a child who has Down's syndrome grows up which can affect their emotional development.

Early childhood

This is a time when the parents and wider family are getting to know the little boy or girl who has Down's syndrome and are adjusting to having a child with additional needs.

Emily Perl Kingsley wrote about this time in her piece, **"Welcome to Holland"**

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So, you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills...and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy...and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away...because the loss of that dream is a very very significant loss. But...if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland.

Depending on the individual, it may be a time when they are worrying about health issues and procedures to be faced.

Of course, some people know in advance they are expecting a child who has Down's syndrome so the process of adjusting to this news can start before the baby arrives.

There is no '*single right way*' to be a parent, including a parent of a child who has Down's syndrome, but most parents will want to do the very best they can for their child. And there is no shortage of advice and guidance from other parents and professionals in the form of books, websites, videos, blogs, forums, training courses etc. This can be overwhelming.

Some people want their child who has Down's syndrome to be *'treated like any other child'* and do not want to make allowances or give them any special treatment. Others will be the total opposite and dedicate all their time and energy to finding out about and implementing all the recommended strategies/diets/therapies etc.

The most healthy and helpful response for you and your family's general wellbeing is probably to try and strike a balance between these two positions. Some specialist information and advice will be needed but following your instinct and getting to enjoy and know your child and their needs, strengths, likes and dislikes and how they communicate, are just as important.

Adolescence/Teenage years

'Mood swings, pushing boundaries, tiredness, feeling confused, crushes, first loves and spending ages in the bathroom… Whilst these changes may occur a little later than in people who don't have Down's syndrome, young people who have Down's syndrome will be just like any other teenager. Sex and relationships, wanting independence, good personal hygiene, needing personal space and building good self-esteem are all issues that you will need to think about as your son or daughter grows up.'

Source: DSA Website

In terms of emotional well-being, adolescence can be a time of increased stress as the young person copes with the changes to themselves but also to some of the expectations around them. They may become more conscious of differences between them and their siblings or peers and this can affect self-esteem.

Things like self-talk and grooves (rituals and routines) can increase around this time and are usually not anything to worry about. However, it can be tricky to know what is "normal teenage behaviour" and what is something to be worried about.

McGuire & Chicoine, in their excellent book *Mental Wellness in Adults with Down syndrome*, give the following pointers:

EXPECT – Young people who have Downs syndrome to respond to physical and hormonal changes associated with puberty in the same way as other teenagers:

- Become more focussed on appearance and personal hygiene
- Have problems with spots
- Get more interested in the opposite (or same) sex
- Begin to masturbate
- Sleep more

Another similarity is in the increasing wish for independence. This, as with other teenagers, can be an area of conflict with parents. Some children may already have a tendency to resist demands and requests from others. This can become more entrenched in the teenage years. Another way that young people who have Down's syndrome may assert their independence is in relation to their 'grooves'. We know that repetitive and compulsive behaviour, along with a liking for sameness, order and tidiness, can form part of the typical behavioural profile of people who have Down's syndrome. Sometimes, a greater insistence on carrying out these behaviours can be a way of adolescents asserting their rights and opposing parental or adult authority, rather than acts of outright rebellion, or angry outbursts such as slamming doors, storming off etc.

A wish for greater autonomy and independence - including things like having their own money, travelling alone on public transport, sleepovers with mates, attending clubs and activities without parents/carers – arise as issues for all teenagers but can be more difficult to negotiate for the young person who has Down's syndrome. They are likely to be more vulnerable than others of their age and there is a natural tendency to want to protect them from possible harm.

See the sections of this resource about **'Self-esteem and self-identity'** and **'Independence, risk and choice'** for further information about the issues covered here. The DSA has a teenage resource ***'Let's talk about relationships and sex'*** that can be purchased on our website.

Imagination and fantasy

Many people who have Down's syndrome enjoy TV, movies and YouTube. The arrival of the tablet computer has made these things very accessible and lots of people who have Down's syndrome become very adept at finding content that they enjoy. Sometimes a fascination with a programme, movie or individual actor can become a real fixation.

As for the general population, soap operas can be especially popular and they can be a good medium for learning about life events, relationships etc. However, some people who have Down's syndrome can find it hard to separate reality from fiction or fantasy. Whilst watching a programme, they may feel as if they are directly experiencing the emotions associated with a particular dramatic incident (for example: a bereavement, trauma, falling in love) as if it is happening to them rather than to a character on a TV screen. Some people may model their own behaviour on things they have seen on TV or worry that sad or bad things they have seen might happen to them.

Nowadays social media forms an increasing part of our lives and many teenagers and adults who have Down's syndrome will want to participate and use Facebook, Instagram etc. As well as needing to put in place some controls to safeguard people from online bullying and other harmful or inappropriate content, it may be important to try and help the person to understand that things that are posted on social media platforms are not

always true, or real. Of course, this may be a concept that is too complex for some young people who have Down's syndrome to understand so information needs to be given at the right level for that individual. There are some useful resources that will help listed at the end of this section.

In their excellent book *Mental Wellness in Adults with Down syndrome,* Dennis McGuire & Brian Chicoine, who have a lifetime of experience in working with people who have Down's syndrome, have some relevant things to say about imagination, fantasy and the role of these in people's lives.

'We have found that people with Down syndrome often have a rich and creative imagination and fantasy life. They easily create fantasies from their rich and fertile bank of visual memories and from favourite movies and TV shows which are also saved in memory. Common examples involve people imagining themselves to be police or firemen, pro wrestling or other sports figures, princesses, heroes and superheroes and of course, movie and music stars……

We have also heard more fanciful tales of marriages, babies delivered, relationships with stars, and accomplishments by the person or significant others that are gross exaggerations or fantasies. Parents, caregivers, and professionals frequently express concerns that such behaviour is "inappropriate" for an adult with Down syndrome. In most cases we do not agree.

When evaluating the appropriateness of such stories and fantasies it is important to consider developmental rather than chronological age. For example, an individual with a chronological age of 27 years may actually have the developmental age of 5 or 6-year-old in terms of abstract thinking, maturity of decision-making etc.

Similarly, the line between fact and fantasy is blurred for many people with Down syndrome……As a result, fantasized characters from movies and cartoons may be easily confused with real-life people and events. With this in mind, creating and believing in fantasies is quite normal and appropriate for most people with Down syndrome.

Another concern is whether made- up stories and fantasies are just "lies" and or even a symptom of psychosis. While we have seen some people with Down syndrome who lie or who have psychotic symptoms, generally we have found that instances of fantasy creation are most simply an indication of an active and creative imagination.

DO'S AND DON'T'S IN DEALING WITH FANTASY

- *Do try to limit a fantasy if it is interfering with work or school or peer relationships*
- *If the involvement is interfering with the person's life, redirect her towards other activities.*
- *When redirecting the person, it may or may not be helpful to tell her that the object of the person's fantasy is not real (e.g., "Rocky is only a character on TV. The man you see in the movie is just an actor pretending to be Rocky.") Often, however, this is not comprehended or accepted. If so, it is not necessary or generally helpful to continue insisting that the character is not real.*

- *When redirecting the person away from the fantasy (such as by limiting access to videos, DVDs, games, etc. that the person is obsessed with), do so in a positive fashion so that you are directing the person away from these objects.'*

Source: D. McGuire & B Chicoine, "Mental Wellness in Adults with Down syndrome: A guide to Emotional & behavioural Strengths and Challenges", Woodbine House, 2006

Fantasies can be positive in that they can help people to while away some free time and they can also encourage creativity (for example: in music, painting and dancing). We all need aspirations and dreams even if they do not come to fruition. But it is important to bear in mind that there may be some negative consequences of fantasy too. Fantasies can end up competing with everyday real life particularly in situations where a person is bored or stressed, or they feel the need to switch off in an environment they find overwhelming. Fantasies may also be misinterpreted by others as a behaviour or mental health problem especially if a person is acting out a fantasy in public.

From early adolescence onwards is a good time to start some more systematic teaching about emotions and emotional regulation. We know from the learning profile of people who have Down's syndrome that this is an area of particular challenge when compared to, for example, practical and self-care skills. So, it will require particular attention, support and guidance. The emotional well-being resources listed at the beginning of this section will be helpful in teaching both understanding of own and other people's emotions and behaviour, and in developing coping strategies. We know that people who have Down's syndrome learn best from experience so this teaching needs to be linked to their own experiences and things they can see.

More serious issues/trauma

Sadly, there are negative experiences that some people go through which, though uncommon, can have a serious impact on emotional well-being and mental health. These are things that many parents may worry about, especially as the person they are caring for develops more independence and wants to be out and about in the world. These things can of course happen at home and at school too. Such traumatic experiences include:

- Abuse, neglect and exploitation…this can be physical, sexual, emotional or financial
- Bullying
- Being involved in or witnessing a serious accident or incident.
- Witnessing domestic violence

It is true that having a learning disability, or disability of any kind, can make people more vulnerable to abuse. Some things that can be helpful to protect people against traumatic experiences and /or help them cope and recover include: -

- Parental/supporter awareness of signs and symptoms of abuse
- Teaching people about their rights and about issues like consent
- Teaching people about what is OK and what is not OK (sometimes called "Keep safe" work)

- Giving people the tools to express themselves and talk about their experiences, both good and bad -as an everyday thing, not just if things are worrying
- Accessing counselling or other psychological support when required
- Getting advice and support from local Safeguarding teams

There are DSA resources listed at the end of this section that can help with teaching about consent and staying safe.

'Common signs

Some common signs that there may be something concerning happening in a child's life include:

- *unexplained changes in behaviour or personality*
- *becoming withdrawn*
- *seeming anxious*
- *becoming uncharacteristically aggressive*
- *lacks social skills and has few friends, if any*
- *poor bond or relationship with a parent*
- *knowledge of adult issues inappropriate for their age*
- *running away or going missing*
- *always choosing to wear clothes which cover their body.'*

Source: National Society for the Prevention of Cruelty to Children (NSPCC)

In recent years we have become aware of some people who have Down's syndrome, often in their young adult life, showing symptoms of mental and physical regression where their condition is not associated with Alzheimer's disease. There is research work being undertaken about regression. If you have any concerns about this issue, please contact the DSA.

Adulthood

As young people who have Down's syndrome move into adulthood, they can experience different challenges. Many people who have Down's syndrome very much look forward to being adults and embrace the identity and the freedoms associated with it. However, they are likely to take considerably longer than typically developing young people to develop emotional maturity and may always need support in some areas of their lives. This can sometimes be a source of conflict as the adult who has Down's syndrome may not understand why they are not "allowed" to do certain things. Helping people to understand their own individual strengths and areas of need/difficulty is a good idea, as well as ensuring that people are supported to have as much choice and independence as possible. There is useful information about these issues in the **'Independence, taking risks and choices'** and **'Self Esteem and Self Identity'** sections of this resource.

It is good if people are able to understand that needing help or support with something is OK and that we all need help sometimes.

Adulthood brings additional rights and responsibilities including such things as voting, marriage, sexual relationships, decisions about health and medical treatment, criminal responsibility and financial autonomy. The **'Independence, taking risks and choices'** section of this resource has information about decision making and the Mental Capacity Act.

The transition to adulthood is likely to mean more life events such as leaving school, changes of college/work, moving into supported living to name but a few. It is also increasingly likely that people begin to experience loss events as they may lose contact with the people, services or activities that they accessed as a child as well as possibly relationships breaking up (there is information about loss further on in this section). Siblings and friends may move away, parents will age and possibly become unwell and there will be bereavements (see our bereavement resource). If the adult who has Down's syndrome stays in the family home, they may become a carer themselves. Our resource **'Changes that can happen in families'** may be useful when discussing siblings leaving home for example.

The DSA has lots of information (including in easy read) about preparing and planning for a person who has Down's syndrome leaving home.

Change is known to be something that we can all find difficult but people who have Down's syndrome may struggle even more with change and work very hard to try and keep things the same. Some of the common life events that involve transition and change (previously described) can trigger stress and anxiety.

The research in Dennis McGuire and Brian Chicoine's book *'Mental Wellness in adults with Down syndrome'* tells us that it is not only loss events like death, divorce etc. that can be triggers for depression or anxiety, or indeed for people becoming physically unwell. Positive events such as starting college or a new job, moving to a new house, getting married also create stress which can lead to changes in mood and behaviour.

To help people better manage transitions and changes:

- Teach coping strategies for feelings of stress, anxiety, sadness or anger. Our emotional well-being easy read resources will help when you are teaching people about coping with feelings.
- Use the information further on in this section about supporting people who have Down's syndrome through times of change, loss and when things go wrong.

Adults who have Down's syndrome are very likely to continue to mature, to learn and to develop skills and confidence throughout their adult lives. They may be able to grasp concepts and to do things that they could not when younger. This applies whatever the level of intellectual delay or disability. They may become ready in their twenties or thirties to move on to greater independence and to tackle things like moving to a new house, starting employment, having a partner. If they are denied these opportunities, they may become frustrated and feel stuck.

Supporting people through times of change, loss and when things go wrong

Sameness and predictability can help people who have Down's syndrome to feel secure and in control. It will be different from person to person but change (including positive change) and loss has the potential to affect people who have Down's syndrome quite profoundly and cause stress.

There are measures you can put in place to help people get on with their daily lives and to cope better with changes when they arise.

If possible, try to support the person to have an understanding that change, good and bad, is part of life for everyone. We know people who have Down's syndrome often find change and the process of change (transition) difficult; not knowing what is going to happen, where to go, what to expect or what you are supposed to do can all cause anxiety. This can be just as true of small day to day changes such as moving on to a new task as it is for bigger life changes such as a much-liked support worker moving on.

'We have found that for people with DS, separation from peers, a teacher, or one-to-one aide; the death of a loved one; a sibling going to college; or even the transfer of a peer to a different classroom can hit a lot harder than you might expect. So, when we see children with DS who are experiencing behavioral or emotional challenges, we often ask about losses to see if this might be playing a role.'

Source: *Supporting Positive Behavior in Children and Teens with Down Syndrome* by David Stein (Woodbine House, 2016)

People who have Down's syndrome can sometimes be good at picking up on forthcoming changes/events they haven't been told about. If there is a significant change on the horizon, it is best to be honest and open about it rather than the person possibly misunderstanding what is happening, or going to happen, and worrying unnecessarily.

With both small and large transitions, giving the person advance warning can really help. In the case of moving on to a new task or getting ready to go home after work for example, you could use a verbal and visual prompt (for example: the person's visual timetable) ten minutes beforehand to prepare the person. Alarms, kitchen timers and sand timers can all be helpful as warning tools for day-to-day transitions of this kind.

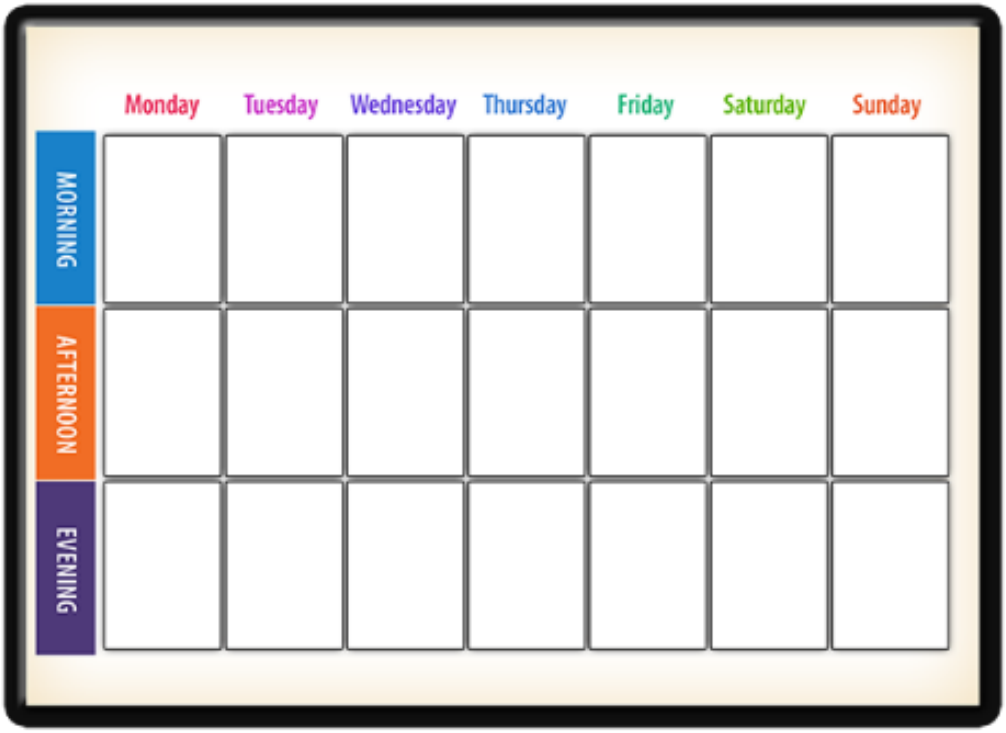
Always think about what an appropriate advance warning might be for the person you are supporting; it will be different for each individual. There is always the chance if you give warning too early before the change/transition, the person will forget. Alternatively, if you give warning too close to the change/transition, there will not be enough time for them to prepare. Some people can get fixated and anxious about things that are going to happen so this means there is a temptation not to tell them until the last minute. Preparation is just as important for these people, but they will probably need extra reassurance.

Here are some ideas to help prepare people for transitions/change:

- **Paper and electronic visual timetables**

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.



- **Social stories**

A social story is a short description of something that is going to happen and why. Social stories are generally used to help a person who has learning disabilities and/or autism to understand how they should respond to specific events/situations that may occur in their lives.

Social Stories™ provide guidance for responding to social situations by clarifying social expectations.

The stories aim to promote an individual's self-awareness, self-calming and self-management.

They may use images or words to present the situation.

Who for?

Social Stories ™ can help any individual of any age who experiences challenges with appropriate social communication.

How to use

Identify a situation in which the person is having difficulty understanding or exhibiting appropriate behaviour.

Some common topics include:

- responding to cues in the environment (e.g. fire drills)
- describing other people's points of view (e.g., some people like loud music)
- defining new routines (e.g. changing classes),
- outlining rules and expectations (e.g. having a substitute teacher),
- or describing an unfamiliar future event (e.g. school trip).

Write the text of the story.

Social Stories™ are usually written in first person from the person's perspective using positive, reassuring language to explain the situation and/or target behaviour. Question words can support the explanation e.g. who, what, when, where and why.

1. Descriptive sentences:

- State the facts (e.g., "My name is ___." Or "The teacher is standing.")
- Include thoughts and feelings of the person and others in the story (e.g., "The teacher will like it when I listen." Or "Many people want to learn.")
- Identify what others can do to help the student if help is needed (e.g. "If I feel upset, my teacher can help by___.")
- Express a shared opinion or reassure the student (e.g. "This is okay.").

2. Directive sentences

- Identify possible responses (e.g. "If I need a break, I can tell the teacher or put the break card on my desk and go to the beanbag.").

- Gently direct behaviour (e.g., "I will try to _____.").

Maintain a ratio of at least 2 descriptive sentences for every directive sentence.

Making the story more descriptive than directive is recommended.

You might consider enlisting the person's help in generating some of the content.

Adding pictures/photos may help to enhance the person's understanding of the text. Try to tailor the format to the abilities and interests of the person and include what will likely happen if he/she correctly performs the target behaviour(s).

Share the story with the person.

New stories should be read frequently and prior to the challenging situation.

The story can be read less frequently as the person begins performing the appropriate behaviours. Eventually, the Social Story™ may no longer be needed.

For some people, periodic reading of the social story may continue to be beneficial long-term.

Assess the effectiveness of the story once the story has been used for a full week.

If the person is not yet beginning to exhibit more appropriate behaviours, stories may need to be rewritten or paired with more visual supports to remind them of the desired behaviours or reinforcements systems.

- **Visiting a new place in advance** may be helpful for some (for example: visiting the hearing clinic in advance of an appointment and meeting the audiologist so the person you support knows where they will be going to have their hearing checked).
- **Photo storybooks** – these may be useful to use in conjunction with advance visits. Take photos during the advance visit (including the person who has Down's syndrome if they are happy to take part) and make a photo storybook when you get home. This can be done on a tablet, PC or on paper. The person can look at this before going to their appointment so they know where they will be going and whom they may be seeing.
- **During times of bigger change and transition try not to make other changes** in the life of the person. Support their normal routines where possible so they have some certainty and predictability.
- **Routines**

Routines are useful for people who have Down's syndrome. Once people have learnt a routine, they are really good at sticking to it. This might be a routine for getting ready in the morning for example. Following a routine helps people know what is happening next and it provides safety and security. It is good to know there is this tendency and to work with, and support it, where possible. Sometimes there may be a need to replace an existing routine with a different and more positive routine.

- **Taking risks**

There will be people who may not be keen on new tasks or taking risks. It is best to approach smaller and new unexpected challenges by working with the person in a positive and relaxed way, so they are happy to try something new. You could create a personalised 'Let's Try it' card for such situations.

Despite our best efforts, life sometimes throws up an unexpected change or events for which we cannot prepare. It might be an unexpected change to a daily routine where you can provide prompts and reassurance to help the person to adapt. If a bigger unexpected event happens, it is important to be up front about what has happened, or is going to happen, whilst being mindful not to overwhelm the person with too much information.

Try to find out what they know and where they are at in their understanding of what has happened (or going to happen) and go from there. Provide opportunities for them to communicate how they feel and what they want. Think about the whole person and their total communication; look out for any non-verbal cues (for example: facial expressions, body language and behaviours) that may give indicate how they are doing.

Self-talk

Many people who have Down's syndrome talk to themselves (also called 'self-talk'). This can be useful if you want to find out what is going on in a person's life or if something is worrying them. Self-talk is often people 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. 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.

The following tips can be helpful at times of unexpected change and/or when things go wrong:

- Try and normalise the situation (for example: *'This is part of life'*, *'it happens to all of us'*) and provide reassurance.
- Acknowledge the person's reaction, how they are feeling or how they might be feeling.
- Where possible try to support the person's usual routines and provide as much structure and predictability in their daily life as you can.
- People can very easily become stuck in a loop with their thinking about something that has happened to them and fixate on a thought or issue. Where you feel it is appropriate, provide some positive distractions (for example: enjoyable activities).
- Monitor how the person is doing and, if necessary, get some professional help from the GP and/or the local Community Learning Disability Team.

Loss and what helps

It is important to think about the degree to which some people who have Down's syndrome may experience changes in their lives that potentially involve loss. Here are some examples to think about:

- Loss of a friend who has moved to a town 10 miles away
- Loss of a support worker who has taken up a new job
- Loss of a sibling who has left the family home to go to university
- Loss of a friend at school due to their leaving school/moving away or the person who has Down's syndrome changing school or class

Whilst no one has a crystal ball with which to predict all such changes, you may sometimes have some warning that a life event of this kind is on the horizon and the chance to put a plan in place to lessen its effect.

Here are some ideas that might help to soften the impact of these losses:

Loss of a friend who has moved

- Help the person you support to continue their friendship
- Set up opportunities for the friends to meet
- Support /prompt them to call/text their friend
- Support/prompt them to keep in touch with their friend via social media/skype
- Think about whether the person can be supported to travel independently to meet up with their friend

Loss of a support worker

- Let the person know what is happening
- 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 a new support worker before the old support worker leaves

- Plan for the new support worker to work alongside the old support worker
- The 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 may take time (this could be 6 months or so for some people) before they feel sadness and a sense of loss. Try to strike a balance by continuing to give support and understanding but also using distractions where you feel they are necessary.

Loss of sibling who has left home

- Let the person know what is happening
- Make time and space for questions
- Maintain routine and consistency
- Support /prompt them to call/text their sibling
- Support/prompt them to keep in touch with their sibling via social media/online
- Think about whether the person can be supported to travel independently to meet up with/stay with their sibling
- Support/facilitate visits to their sibling
- At this time of change think about accentuating the positive things in the person's life along with ways to give their self-esteem a bit of a boost
- Keep them busy – check to see how they are doing and provide positive distractions if you think they are perhaps over focusing on their sibling

Loss of a classmate at school
(due to their leaving school, moving away or the person who has Down's syndrome changing school or class)

- Have a chat with the friend and/or their parent (depending on child's age) to explore ways they can stay in touch with your child
- Try and mark the life change with a leaving event
- Set up opportunities for the friends to meet and enjoy activities they can both enjoy
- Support /prompt your child to call/text their friend
- Support conversational/friendship skills where needed
- Support/prompt your child to keep in touch with their friend via social media/online
- Have some visual reminders of your child and their friend around the home (for example: photos on the fridge and/or a memories book of the things they have shared and done together)
- Mark each other's Birthdays

DSA resources

- ***Listen to me – Growing up and thinking about being an adult*** **(easy read)**
- ***Bereavement***
- ***Leaving home, housing and day to day support*** **resources for adults, many easy read, on the DSA website**
- ***Staying safe from sexual abuse*** **(easy read)**

- ***Let's Talk about Relationships and Sex: Teenage Resources***
  These sets of resources for teaching teenagers who have Down's syndrome are available at the DSA shop. They cover:
  - Consent
  - Privacy and Boundaries
  - Relationships
  - Sexual Acts
  - Sexuality, Genders and Safe Sex
  - A set of illustrations for private body parts and sexual acts

- ***Let's Talk about Relationships and Sex: Adults***
  This comprehensive 8 session training package for adults who have Down's syndrome provides a trainer's guide and accessible teaching resources, activities, workbooks and evaluations covering:
  - Rights
  - Consent
  - Privacy and boundaries
  - Sexual acts
  - Sexuality, gender and safe sex
  - Relationships
  - Online safety and self esteem

The training package is available at the DSA shop.

Other resources

Books Beyond Words https://booksbeyondwords.co.uk/

- *Finding a safe place from abuse*
- *I can get through it*
- *Jenny speaks out*
- *Bob tells all*
- *Hug me, touch me*

Mental Wellness in Adults with Down syndrome by Brian Chicoine and Dennis McGuire (Woodbine House, 2006) (available from any large book seller)

Contact the DSA

If you have any questions about the issues covered in this section, you can call DSA's Helpline (Tel: 0333 1212 300) or email using **info@downs-syndrome.org.uk**

Difficulties and coping strategies

A person who has Down's syndrome may not recognise that they are anxious as they may not understand the physical symptoms that can accompany anxiety. They may not be able to verbalise to another person how they are feeling. It is helpful to start talking about body sensations and feelings from a young age and helping a person to name their feelings.

DSA well-being resources for people who have Down's syndrome that are relevant to problems and coping strategies:

- **Anger**
- **Stress Bucket**
- **How am I?**
- **Let's talk about feelings**
- **Mindfulness**
- **Things I do to relax (video)**
- **Things you can make or buy**
- **Relaxation activity (audio)**

Stress and Anxiety

What is stress?

Stress is something that we all feel at certain times and it is a completely normal reaction to feeling under pressure or threatened.

A healthy amount of stress can help us to get things done and deal with the demands of everyday life.

However, the word stress is often used to describe the bodily reactions that people experience when the demands made on them are greater than their ability to cope. At these times people can often feel under too much pressure and even overwhelmed and we may call this feeling anxiety.

People who have Down's syndrome will experience stress and anxiety the same as everyone else and for the most part this will not develop into a mental health issue. However, for some people who have Down's syndrome their stress and anxiety may get in the way of them living their life and this could lead to having a diagnosis of general anxiety disorder or obsessive compulsive disorder.

What is anxiety?

Anxiety is what we feel when we are worried, tense or afraid, particularly about things that are about to happen, or which we think could happen in the future.

Anxiety is a natural human response when we perceive that we are under threat. It can be experienced through our thoughts, feelings and physical sensations. Anxiety is our reaction to stress.

What causes us to feel stressed or anxious?

What makes a person feel this way is very personal and may change as it can be caused by a number of factors such as:

Unfamiliar situations	Environmental issues	Being with other people	Having too many things to do
Change	Money problems	Holidays	Not having friends
Health issues	Being made to do things we don't want to	Expectations	Waiting
Lack of control	Not being understood	Loss of a friend or family member	Transition

People who have Down's syndrome will experience anxiety for the same reasons as anyone else. It may have less, the same, or a worse effect for the person. If a person does not understand what has been asked of them or what is happening when, then this can result in them becoming anxious. Many people who have Down's syndrome will need help to understand the concept of time and may need visual support in understanding what is expected of them and the time frame in which it needs to happen.

Transitions

This is a time when it is particularly important to look out for signs of anxiety. A person who has Down's syndrome may find transitions difficult and feel quite worried about any changes in their life. It is helpful to start preparing for change as early as is possible and to introduce new buildings, journeys and people slowly. Arranging a number of pre-planned visits, practising journeys and making videos of new people such as teachers can help the person to feel less worried. The **'Life stresses and strains'** section of this resource has further information about preparing for transitions.

What happens when we are anxious?

Anxiety can cause many different symptoms. It might affect how a person feels physically, mentally and also how they behave. It's not always easy to recognise when stress or anxiety is the reason that someone is feeling or acting differently.

Here are some of the things that a person might experience:

Physical	Mood	Behaviour
• Fatigue • Headaches • Upset Tummy • Sweating • Chest pain • Rapid heartbeat • Low immune system	• Irritability • Ruminating • Restlessness • Racing thoughts • Overwhelmed • Tearful	• Drinking more alcohol • Poor appetite or over-eating • Social withdrawal • Poor memory • Not being able to find the right words • Talking too fast

A person who has Down's syndrome may not recognise that they are anxious as they may not understand the physical symptoms. They may not be able to verbalise to another person how they are feeling. It is helpful to start talking about body sensations and feelings from a young age and helping a person to name their feelings. Our ***Let's talk about feelings, How am I?*** and ***Stress bucket*** resources can help with this.

Behaviour is a way that a person can let others know that something isn't right and some of the behaviours that may indicate this are:

- Verbal or Physical Aggression
- Self-harm
- Pacing
- Repetitive behaviours
- Withdrawal
- Incontinence
- Refusing to eat/overeating

This is not an exhaustive list and there may be more that you can add.

As parents and carers it can be difficult to know what the cause of a behaviour is, particularly as it may not happen in the timescale we think it should, but if a behaviour is unusual for a person then it may be that they are worried about something that has happened or is going to happen.

Our ***Supporting behaviour positively*** resources can help.

Seeking professional help

Sometimes people wrongly think that the Down's syndrome (or another condition) is the reason for a behaviour however if there has been a change in behaviour such as an increase in aggression or withdrawal it is advisable to seek help.

The mental health needs of people who have a learning disability have been overlooked in the past and this led to a number of papers being written and in 2016 the NICE guidelines *Mental health problems in people with learning disabilities: prevention, assessment and management* were published. These guidelines highlight that staff and others caring for people who have learning disabilities should consider a mental health problem if a person who has learning disabilities shows any changes in behaviour, for example:

- Loss of skills or needing more prompting to use skills
- Social withdrawal
- Irritability
- Avoidance
- Agitation
- Loss of interest in activities they usually enjoy.

There are now specialist teams in both adult and children's services who will work with people who have Down's syndrome and mental health issues where they are impacting on their life.

Details of your Community Learning Disability Team (adults) or Child and Adolescent Mental Health Service (CAMHS) (children and teenager) can usually be found on the local NHS Trust website.

When does anxiety become a disorder?

A person will be diagnosed with General Anxiety Disorder when they have the following:

- Excessive anxiety and worry occurring more days than not for at least 6 months, about a number of events or activities.
- Difficulty controlling worry
- The anxiety and worry are associated with 3 or more of the following 6 symptoms (with at least some symptoms present (for more days than not) for the past 6 months)
- Restlessness or feeling keyed up or on edge
- Being easily fatigued
- Difficulty concentrating or mind going blank
- Irritability
- Muscle tension
- Sleep disturbance (difficulty falling or staying asleep), or
- The worry is not confined to features of another disorder
- The anxiety, worry or physical symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning
- The disturbance is not due to a substance and does not occur exclusively during a Mood Disorder or a Psychotic Disorder.

How can we help someone who has Down's syndrome when they are feeling anxious?

At the time that a person is showing any signs of anxiety it is important to offer reassurance and not to tell them they should not feel that way.

If appropriate ask them what would help and what they would like from you.

Perhaps fetch something you have previously identified as helpful.

How can we prevent anxiety?

We will not be able to prevent all anxiety but there are things that may reduce levels of anxiety such as:

- Planning ahead
- Using visual aids
- Breaking up tasks into achievable parts
- Allowing a person to express themselves through whatever medium works for them to help prevent a build of anxiety
- Teaching a person what anxiety is, how it feels and what they can do when it happens. Our ***Let's talk about feelings, How am I?*** and ***Stress bucket*** resources can help with this.
- Allowing time and space
- Managing changes - The **'Life stresses and strains'** section of this resource has further information about managing changes

Strategies for helping a person who has Down's syndrome to reduce stress and anxiety

- Ensuring that a person does not have too much built into their day
- Helping someone to focus on the things that went well, not the one thing that didn't
- Helping someone to take notice of the world around and what they are feeling. Our feelings resources (referred to above) and our ***Mindfulness*** resource will help
- Supporting someone to learn how to let go of anger and resentment and to forgive others
- Keeping active - exercise is proven to improve mental wellbeing and can be as simple as a short walk or dancing in the kitchen
- Eating healthily
- Ensuring the person has enough sleep
- Making time to regularly check in around how they are feeling
- Offering time to talk about worries
- Supporting a person to access professional help if needed
- Allowing a person to express emotion
- Spend time with people who understand

For some people listening to a relaxation recording can help – our **Relaxation audio** is here. It might be useful to try it out a few times before introducing it when someone is feeling anxious. Our **video about relaxing** may also be helpful.

It is important to look after yourself! Supporting a person through anxiety can be very difficult. Make sure that you also spend time doing the things that you enjoy and which help you to cope. Please see **'The emotional well-being of parents, carers and supporters'** section of this resource for further information.

Anger

What is anger?

Everyone gets angry from time to time – some anger is good for all of us in certain situations. We all feel angry at times. People with learning disabilities are no different in this regard. However, they may have difficulty understanding, or coping with their angry feelings. Or, people could feel under pressure not to get angry, and to be calm and happy all the time. This is unrealistic.

Anger is a reaction – it could be to being offended, ignored, provoked or denied. Everyone has their own triggers that make them feel angry and these can be very personal to that individual.

Some of the things that tend to make people angry include: -

- People not doing what they have promised
- Being interrupted
- People being rude
- Being teased or bullied
- Being shouted at
- Call centres
- When your team lose a match
- Bad drivers…….and so on

People who have Down's syndrome may experience things that make them angry such as:

- Not being listened to
- Not being understood
- Not being given choices
- Being called names
- Not being allowed independence

Anger is not the same as aggression – aggression is behaviour that could or does harm to another person, or to things. Anger may result in aggression, but it doesn't always. And sometimes people can be aggressive without anger. It is OK to be reasonably angry, but you can't be reasonably aggressive.

In our ***Anger*** resource for people who have Down's syndrome we talk about the Anger Rules, to try to explain this.

The Anger Rules

Anger is a natural feeling. Everybody gets angry.

It is OK to feel angry BUT…….

Don't hurt others

Don't hurt yourself

Don't hurt objects/things

Do talk about it

Everyone experiences anger in their own way. The anger response affects how we feel in our bodies but also what we think and feel, emotionally.

These are some of the **feelings** that people get when they become angry

Feeling out of control	Tense muscles	Heart racing/pounding	Breathing quickly
Feeling threatened	Shaking	Hot/sweating	Lightheaded
Stomach churning/butterflies	Fist or teeth clenching	Feeling that things aren't fair	Frustration

Often, there are signs in a person's **behaviour** that they may be becoming angry –these might include:-

- Pacing
- Shouting/swearing
- Banging/crashing around
- Gesturing (for example: waving fist)
- Sulking/angry silence
- Glaring/staring
- Advancing/moving towards
- Throwing things

People may have a range of coping strategies for when they feel angry, or they may have very few, and be more prone to outbursts of aggression, or self-harm. Most of us learn to manage our anger, especially in public places, using a range of strategies which may include storming off, or walking calmly away, taking some deep breaths, counting to 10, lighting a cigarette, going for a run, talking to a friend, slamming the door etc. Some of these strategies are clearly more positive and healthier than others.

People who have Down's syndrome, along with many other people who have a learning disability, may not find it easy to understand their own feelings, and to recognise that

they are angry. Even if they do, they may not be able to know why, and what to do about it.

As with other emotions, it is really helpful for people who have Down's syndrome to be taught about anger, what it is, how they experience it, their triggers, the Anger rules, and ways of coping.

Our ***Anger, Let's talk about feelings, How am I?*** and ***Stress bucket*** resources can help with that.

Dealing with anger

Understanding what triggers an angry response in someone can help with both preventing challenging behaviours but also with enabling the person to have a plan for what to do in that situation. Whilst getting angry is part of normal life, none of us would like to be constantly faced with situations that wind us up.

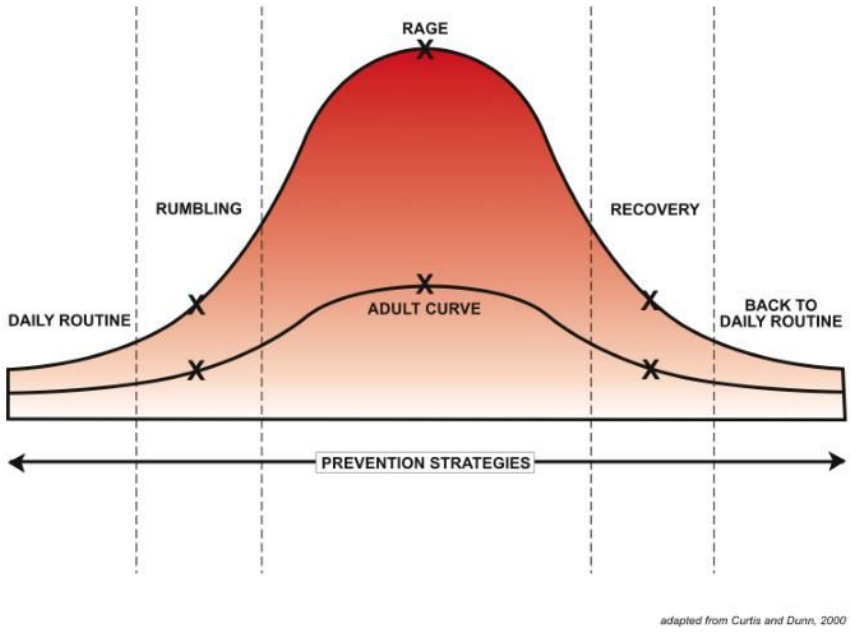
It is good to get people to practise their coping strategies by providing support and prompting. Social stories can be very helpful. Sometimes, depending on the person's understanding, it can also be helpful to review incidents where they became angry and think about what happened, how they felt, what they did, and what they might do differently.

There is further information about social stories in the **'Life Stresses & Strains'** section of this resource.

'Meltdowns'

In everyday use, *'meltdown'* is a term used to describe the condition of a person who, under pressure or stress, has reached a point where they can no longer cope, or have *'snapped',* become angry, tearful or overreacting.

The term is also used, more specifically, to describe the extreme actions of some people who have disabilities, when they are in an intense *'out of control'* state of behaviour. This is **not common with people who have Down's syndrome** but may occur for some people with more complex needs, such as a dual diagnosis of autism, as they are more susceptible to becoming totally overwhelmed and unable to cope.



Source: Myles, B., and Southwick, J (2005) *Asperger Syndrome and Difficult Moments – practical solutions for Tantrums, Rage and Meltdowns* [2nd edition]. AAPC

The diagram above illustrates different stages in the rage cycle, or meltdown. Whilst distraction and redirection may work early on in the cycle, once the person has reached a certain point they are likely to be unresponsive to attempts to interrupt the behaviour and it needs to be left to run its course, which can take some time, leaving the person and their carers exhausted and drained.

If the person you are caring for experiences meltdowns, try to remember that they are best understood as a **panic attack**. This is not a battle to be lost or won, but a crisis to be managed. The idea is to try and act as an emotional brake for the person and to avoid fuelling the crisis - stepping back and giving space, reducing verbal language, offering reassurance, staying as calm as you can yourself, guiding the person to a safer place if possible, making the environment safe by removing objects that could be harmful (if it is safe to do so), can all help to put the brakes on.

As the person starts to calm, you can then offer comfort and reassurance. Avoid asking questions or discussing the why's and wherefores at this point. You may wish to seek the support of behaviour specialists or support services.

What is available may vary from area to area and may be different depending on whether the person is a child or adult but there is often a service specialising in behaviour support for more challenging situations, where the workers have specific training. You could ask your social worker about this, or contact the Community Learning Disability team (CLDT) (adults) or local Child and Adolescent Mental Health Service (CAMHS). Details of these services can usually be found on your local NHS Trust website.

Obsessive Compulsive Disorder

It is not uncommon for people who have Down's syndrome to have a tendency towards sameness and repetition. This may be following set routines, liking to do things in the same way, being very clean and tidy. These can be helpful in helping a person to complete tasks.

Dr Dennis McGuire (co-author of *Mental wellness in adults with Down syndrome*) calls these rituals and routines 'Grooves' and while these behaviours can sometimes be seen as stubborn, they mostly have benefits for the person. For some people who have Down's syndrome these can become problematic and can result in thoughts or behaviours becoming rigid or stuck. This may lead to a diagnosis of Obsessional Compulsive Disorder (OCD).

What is OCD?

Obsessions are thoughts that preoccupy the mind.

Compulsions are acts that one feels compelled to do and in OCD the compulsions are linked to a desire to reduce the anxiety that arises from the obsessions.

OCD does seem to be more common in people who have Down's syndrome than in the general population although it is still rare. The difference can be that while people ordinarily want to get rid of their obsessions and compulsions and see them as problematic, people who have Downs syndrome can often have no desire to change them. Stress, physical health problems, life events could all contribute to the development of OCD.

If you are concerned, please seek professional advice. Diagnosis of a mental health condition should be made by a specialist team who will usually request records of relevant behaviours, including changes from what is typical for the person, and details of the things that cause them stress (stressors).

Sadness and feeling low

We all have off days and it is very natural to feel sad and/or low sometimes. Some people will be able to let you know how they are feeling and why, but others may not. Our ***Let's talk about feelings*** and ***How am I?*** resources may help the person you support to express how they are feeling.

For many people who have Down's syndrome, changes in their behaviour are often an indication that something is wrong. For example, some people may become much more rigid with their daily routines and rituals during times of worry and stress.

Whilst self-talk can be a very helpful, self-soothing strategy for many people, an increase or change in how they talk to themselves or what they are saying (for example: negative thoughts or anger directed by the person at themselves) may be an early indicator that all is not well for them.

It will be helpful to try and think about what may have led to the change in the person's mood. This may give you some clues as to what you can do to help them to feel better. For example, have there been any changes or events in their life that may have contributed to their low mood? Are they unwell? Have their sleeping patterns or appetite changed? Of course, it may not always be possible to identify a single cause or causes.

What helps when someone is feeling sad/low will be different from person to person.

Here are a few ideas:

- Make some positive changes to the person's lifestyle
- Provide the opportunity and means for them to express how they are feeling
- Create opportunities for the person to feel they have accomplished something that is important to them
- Would more/different activities help?
- Would providing more freedom and control help?
- Boost self-esteem and emphasise the good things in the person's life and all that they are good at
- Alleviate pressure and stress where you can
- Encourage participation in exercise/sport and changes in diet
- Provide enjoyable and interesting distractions – it can be very easy for people who have Down's syndrome to get stuck in a thought pattern or on a particular issue. Distraction can help!
- Time with friends
- For some people, time alone in their own space might be helpful (keep a discrete eye on the person, too much time alone will probably not be helpful)

If you have concerns about the emotional well-being of a person who has Down's syndrome, make an appointment with their GP. It is always a good idea to get the person checked out by the GP if their low mood persists as they may have a health

problem that is causing, or contributing to, their sadness and changed mood. Poor sleep, thyroid, hearing and sight should be discussed and checked as these are common health issues in people who have Down's syndrome.

The possibility of depression should also be considered. Depression is at least as common in children and adults who have Down's syndrome as it is in the general population and affects them in the same way. It is much more than just feeling sad or low for a while. There are a wide range of symptoms, some more common than others, which persist for at least two weeks and often considerably longer. You will find a list of common symptoms in the DSA's health series depression resource. Dr Kerim Munir (Boston Children's Hospital) has written that children and adults who have Down's syndrome and symptoms of depression often lose the ability to enjoy many activities they used to love, they lose skills and they become very withdrawn. Depression may have appeared relatively quickly or may have developed gradually over many months.

Depression is not part of the condition or inevitable, but it is one of the most frequently diagnosed mental health issues for those who have Down's syndrome.

Grief and bereavement

Where a friend or family member has a terminal illness and/or is expected to die, it is important to give the person who has Down's syndrome an honest and straightforward explanation about what is happening or going to happen. This information should be given at a pace, and in a manner, that is right for the individual. Acknowledge and normalise the person's feelings and give them space and time to express how they feel. Try to maintain the person's familiar routines so they continue to have some stability and predictability in their daily lives. Include the person in, and/or facilitate visits to, the person who is dying according to individual need and preference. The person you support may want time alone with their friend or family member.

If they are happy for you to do so, let the important and relevant people around the person who has Down's syndrome know what has happened or is about to happen.

Top ten tips for breaking bad news to people who have learning disabilities

The ten top tips for breaking bad news to people who have learning disabilities (see below) have been developed by Dr Irene Tuffrey-Wijne and her team at St George's University of London.

Ten top tips for breaking bad news

1. Don't avoid the issue

Bad news doesn't go away, and it is our responsibility to help people cope with it in the best possible way. That includes giving crucial chunks of knowledge at the right time – not simply hoping that someone will pick up the knowledge somewhere, somehow.

2. Anticipate questions – and anticipate a lack of questions

Anticipate that there may be awkward questions and be ready to answer them if you can. Perhaps think these answers through with someone else first.

Anticipate that someone might ask unrelated questions, talk about something completely different or begin a distraction activity. Do not assume he hasn't heard you or is not reacting.

3. Make sure you understand the question

Even something as seemingly clear-cut as the question 'Am I going to die?' is not always straightforward. It could mean 'Am I going to die very soon/today?' or 'Am I going to die at all, ever?' or 'Am I going to die exactly in the same way as Dad did?' or 'Is this illness going to kill me and what is it going to be like?' In addition, we don't know what someone means and understands by 'die'. The honest answer to this simple question could therefore range from 'yes' and 'no' to 'I don't know'. To find out what someone means, you could try asking: 'What makes you ask that question?' 'Why do you think that?' 'What do you mean?' 'What do you think?'

4. Be honest (and admit what you don't know)

You don't have to tell someone everything you know (remember to build knowledge bit by bit), but you should not tell a lie. Be very aware of the risk that you are paternalistic – it is easy to misjudge someone's need for information.

Stick to statements that you know are true and that you believe yourself. Don't say 'You're going to live in a lovely new home and you will be very happy there' if you don't know for sure (and you won't) that he will find the new home lovely and that he will be happy. Don't get into complicated explanations of what happens after death unless you are absolutely sure that you both share the same beliefs about this.

Never pretend that you know something when you don't. It is OK not to have all the answers – nobody does! However, if the question is important (as most questions are), see if there is anyone else who could answer it: 'I don't know. Shall we ask the doctor/the manager/your brother about that?'

5. Allow feelings of sadness…

It is OK to cry and be upset. People with intellectual disabilities can be very upfront with their emotions. Distress, worry, anger, excitement and happiness can all surface very quickly, triggered by something seemingly minor. It is important to allow it. Remember that it is not you who has caused the tears – it's the bad news. You can't, and shouldn't, prevent someone's distress, but you should offer support. Often, the best support you can give is simply not to turn away from distressing emotions, and not to try and make them better.

6. … including your own!

It is also important that you have space for your own emotions. It can be very helpful for people to see that others have sad feelings too. It validates their own emotions and it can bring home the message that the news is bad.

If things become overwhelming for you, just take some time out to regain some emotional balance, and talk some more later. If it remains really difficult for you to broach the subject of the bad news without getting upset, ask others to help you.

7. People have a right NOT to know

People have a right to know the truth, but they don't have a duty to know it. Denial, or simply not thinking and talking about the situation, can be a very important coping mechanism. Never force information on someone who doesn't (yet) want to hear it. Don't talk about a situation if someone clearly doesn't want to talk or think about it.

8. Don't overdo it

Don't talk for too long. Tell someone what he needs to know, give him a chance to ask a few questions, and leave it at that. Don't push it. Do ask yourself, though, whether someone is ignoring the bad news because he hasn't understood – in which case you need to help him understand more; or because he is using denial – in which case you should respect his need not to think about the bad news.

9. Repeat the information

Repeat key information at different times and in different ways. This can be with words, pictures, experiences – anything you can think of.

10. Get expert advice

Don't hesitate to consult an expert if you feel you need to. Depending on the situation, ask for help from intellectual disability professionals, doctors, specialist nurses, managers or colleagues.

Source: http://www.breakingbadnews.org/

The grieving process for someone who has Down's syndrome is the same as it is for anyone else. However, for some people it may take longer and show itself in ways that are not instantly recognisable. Some people who have Down's syndrome may have a delayed response to grief; this may be up to 6 months or more after their loss. It may be that people take longer to understand the finality of death and their own thoughts and feelings.

Grieving may be complicated for people who have Down's syndrome by difficulties around placing events in time and their strong visual memory. We know of people who speak about the loss of loved ones in very current and immediate terms even though they died many years ago. Even years after the death of loved one, some people may behave as if they are vividly experiencing the loss because their strong visual memory makes them think and feel as if it is happening in the present. In such instances, it would be very easy to assume, without knowledge of a person's history, that their loss was very recent.

What helps

Always give the news of a death with honesty and at a pace suited to the person. The news of a death should not be kept from a person in an attempt to protect them.

Always use straightforward language in order to avoid misinterpretation. The use of terms such as *'death'* and *'died'* are preferable to terms such as *'passed on'* or *'gone to sleep'*. Visual aids such as pictures or drawings and easy read written materials will help.

The person should be given the choice as to whether or not they wish to take part in the rituals associated with death, such as attending a funeral. If the person is unable to choose directly, it is advisable to involve them as fully as possible. Involvement in non-verbal rituals may be particularly helpful for someone who has Down's syndrome.

It is important to allow the bereaved person to have the opportunity to choose mementoes by which to remember the deceased person and to act as a focus for their feelings.

Avoid major change at this confusing and distressing time. The person may find it comforting to take refuge in their daily routines and familiar surroundings. Helping them to maintain some continuity and connection with life before the bereavement is essential to recovery.

Always give the person space and time in which to express their feelings. Our ***How am I?*** resource may be helpful. Some people may, understandably, want time on their own. If the deceased is a family member, it may be helpful to create opportunities for the person who has Down's syndrome to communicate their feelings to someone outside of the family. Your local Community Learning Disability Team (CLDT) (adults) or Child and Adolescent Mental Health Service (CAMHS) may be able to offer advice and support. Details of these services can usually be found on your local NHS Trust website.

Remember that everyone who has Down's syndrome is different. It may take many months for some people to realise that the dead person will not come back. For some people life will get back to normal quite soon after someone dies. This might be because they knew that the person was going to die and had worked through their feelings before the death. Some people may experience strong feelings of loss for months or even years. As time passes, as with all of us, the person who has Down's syndrome should reach a point where they can remember good things about the dead person without being very sad at the same time. Naturally, dates such as the dead person's birthday or the date when the person died will sometimes bring back the feelings of sadness. Memories are important, it can help for the person who has Down's syndrome to talk about the person who died, what they were like, and what they used to do together when anniversaries arise. Non-verbal rituals and visiting familiar areas or the person's grave can be helpful.

DSA resources

- ***Supporting behaviour positively***
- ***Depression in people who have Down's syndrome***
- ***Bereavement***

Other resources

Foundation for People with Learning Disabilities

All about feeling down – An easy read booklet for young people with learning disabilities https://www.mentalhealth.org.uk/learning-disabilities/publications/all-about-feeling-down

Feeling down: Looking after my mental health - An easy read guide for people with learning disabilities https://www.mentalhealth.org.uk/learning-disabilities/publications/feeling-down-looking-after-my-mental-health

Books beyond words https://booksbeyondwords.co.uk/

- *Ron's Feeling Blue*
- *Sonia's Feeling Sad*
- *When Dad Died*
- *When Mum Died*
- *When Someone Died*

Grief support for the young in Oxfordshire *Hand-In-Hand* https://www.seesaw.org.uk/

Mental Wellness in Adults with Down syndrome by Brian Chicoine and Dennis McGuire (Woodbine House, 2006) (available from any large book seller)

Contact the DSA

If you have any questions about the issues covered in this section, you can call DSA's Helpline (Tel: 0333 1212 300) or email using **info@downs-syndrome.org.uk**

Spirituality

'Looking at the stars thinking about the people I love.'
(An adult talking about things that make him feel good)

Spirituality is about the human search for meaning, purpose, value and hope and it is increasingly seen as a basic human need, which supports both mental and physical health.

DSA well-being resources for people who have Down's syndrome that are relevant to spirituality.

- **Mindfulness** (easy read)
- **Things you can make** (or buy)

What is spirituality?

Spirituality is an important part of emotional well-being. It is a word that is often used although it's sometimes a little difficult to explain; it can mean different things to different people. Many of us will associate spirituality with religious practice. Religion can play a very important part in the lives of people who have Down's syndrome. There are many people who have Down's syndrome, of diverse faiths, who are active members of their religious communities. Within those communities, they find acceptance, friendship and meaning.

In the early 2000s the ***Foundation for People with Learning Disabilities*** did some work with people who have learning disabilities, parents and professionals about spirituality. People felt that spirituality had to do with such things as the search for meaning and what is most important in life, what gives value, hope, friendship and purpose as well as, for some people, their relationship with their God. For some this involved religion, but for many others the spiritual search was carried on without the use of formal religion or belonging to a faith community.

'The people with learning disabilities we spoke to talked about spirituality in different ways. Some people said it was about God. They felt that God loved them and cared for them and that this was the most important thing in their lives. Other people thought that spirituality was about having friends and this gave meaning to their lives. People felt that it was important they belonged to a group or a community. Some people liked to go into the countryside. Some liked music and art.'

Source: *Spirituality – Easy read summary*, Foundation for People with Learning Disabilities

Spirituality, although it clearly includes religion, has come to have a broader meaning. Professor John Swinton (Chair in Divinity and Religious Studies, University of Aberdeen) has defined spirituality as *'the human quest for meaning, purpose, self-transcending knowledge, meaningful relationships, love and commitment, as well as the sense of the Holy amongst us.'* (Swinton, 1999)

'People with learning disabilities expressed a desire to have this dimension of their experience recognised and supported. Friendship was a primary conduit through which people expressed their spirituality and had their spiritual needs met. Friends are important because they love me.'
Source: *Why are we here? Spirituality and the lives of people with learning disabilities* (Updates volume 5, Issue 11, May 2004, Foundation for People with Learning Disabilities)

How to support spirituality

Here are some things you can do to support spirituality

- Help the person you support to attend a place of worship (according to individual preference and belief)
- Encourage creativity as a form of self-expression
- Facilitate meaningful activities; these could include taking part in the arts, employment and/or the time and means to enjoy nature
- Encourage a sense of purpose, belonging and meaning in the life of the person you support (according to individual needs, preferences and wishes)

Contact the DSA

If you have any questions about the issues covered in this section, you can call DSA's Helpline (Tel: 0333 1212 300) or email using **info@downs-syndrome.org.uk**

Bibliography

Understanding Emotions in People with Learning Disabilities, Surrey & Borders Partnership NHS Trust, Pavilion Publishing, 2012

Mental Wellness in Adults with Down syndrome by Brian Chicoine and Dennis McGuire, Woodbine House, 2006

Mental health problems in people with learning disabilities: prevention, assessment and management, NICE, 2016

Supporting Positive Behavior in Children and Teens with Down Syndrome by David Stein, Woodbine House, 2016

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

Down's Syndrome Association

National Office

Langdon Down Centre,
2a Langdon Park, Teddington,
Middlesex, TW11 9PS

t. 0333 1212 300
f. 020 8614 5127
e. info@downs-syndrome.org.uk
w.www.downs-syndrome.org.uk

Wales

e. wales@downs-syndrome.org.uk

Northern Ireland

e. enquiriesni@downs-syndrome.org.uk

DSActive
Activities for people with Down's syndrome

www.dsactive.org

WORKFiT®
Connecting employers and employees

www.dsworkfit.org.uk

LANGDON DOWN MUSEUM OF LEARNING DISABILITY

www.langdondownmuseum.org.uk

Langdon Down centre

www.langdondowncentre.org.uk

Down's Syndrome Association
A Registered Charity No. 1061474

© Down's Syndrome Association 2020

WorkFit® is a registered trade mark of the Down's Syndrome Association. Photographs courtesy of Viktoriia Oleinichenko | Dreamstime.com