

Emotional well-being



Well-being

What does it look like and what to look out for

Our resources and Information Team are 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, then 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

What's in this resource?

This booklet is about well-being and, in particular, about the well-being of people who have Down's syndrome.

Some people who have Down's syndrome may have difficulty expressing how they are feeling. It may be hard for parents and carers to recognise the early signs that a person they care for isn't feeling good.

This booklet includes information gathered from parents and carers and people who have Down's syndrome.

What do we mean by well-being?

The Oxford English dictionary defines well-being as the state of being comfortable, healthy, or happy.

This will be different for everyone and mostly we don't pay much attention until we are not feeling these things!

Our well-being may be dependent on many of the following contributing factors. A good balance will look different for each person.



There are many factors that affect how we feel.

Our **physical health** can have a big impact such as when we are in pain and discomfort, or we have an illness.

Some people may have chronic or persistent pain, this means it lasts for more than 3 months and can be the result of an underlying condition.



The amount of **sleep** we get will also affect our mental and physical well-being, including how tired we feel day today.

Chronic sleep deprivation can impact on our immune system and brain function.



Our level of **physical activity** can also contribute to how we feel.

Even gentle and small regular movements can have a big impact on our well-being.



Having some level of **engagement in activities that are meaningful** contributes to how we feel.

Our well-being is dependent on having things that we enjoy in our lives such as interests and hobbies.



Connecting with other people is crucial to our well-being and this can happen in person, online, one to one or in a group.



Life factors and events can cause ongoing stress, anxiety or worry that may negatively impact on well-being.

Well-being in people who have Down's syndrome

People who have Down's syndrome experience the full range of human emotions that we all feel. In fact, in some cases people who have Down's syndrome can be more attuned to feelings and the emotional environment they are in.

It may be that having Down's syndrome means life events such as change, loss and conflict have the potential to affect a person to a greater degree.

The factors that may contribute to this include:

- heightened empathy
- sensitivity to conflict in others
- difficulties in expressing thoughts and feelings verbally

Of course, these factors will be present in each person to varying degrees as everyone is an individual.

As people may not always (or ever) be able to verbally express inner thoughts and feelings, behaviour is often a good indicator to changes in someone's well-being. Behaviour may also be an indicator of physical discomfort.

Having a grasp of what is typical for an individual in terms of functioning, abilities, behaviour and routine will help us to spot when a change has occurred.



How do we know that someone is well?

When we ask someone how they are, they may be able to verbalise but they may not.

Body language also gives us clues as to how a person is feeling. For example, when we are happy, we might smile or giggle and we might make certain physical movements.

Some people who have Down's syndrome may use stimming when they are happy (arm or hand-flapping, finger-flicking, rocking, jumping, spinning or twirling, head-banging) and some people use it when they are not feeling well and so it is about knowing the person.

It may be harder to recognise when a person is calm and well; it may be the absence of a behaviour that lets us know all is ok.

In the box below are a few things that parents/carers have told us are indicators for the person they care for.

Their speech flows more easily.

They are using more verbal communication.

They can make decisions.

They can indicate or verbalise wants and needs.

They are able to make choices.

They appear calm and relaxed.

They can settle to sleep at night.

They are willing to engage with tasks and activities.

You may have other things that you can add to this list.

What might impact on well-being?

We have already mentioned general things that can impact on a person's well-being and these will all affect a person who has Down's syndrome.

In addition to those previously mentioned, below is a list that parents/carers told us can affect the person they care for:

- Lack of structure and routine
- Change in routine
- Not seeing important people in their life
- Not being prepared for change
- Overload of information, particularly verbal
- Expectation too high

You may have more to add to these.

In the box below are things that people who have Down's syndrome told us affect their well-being.

When things don't happen as we want.

Not feeling prepared.

Being rushed.

Health appointments.

People leaving or passing away.

Other people's emotions.

Other people being unwell.

Being tired

Not being able to see friends and family.

Not having enough to do.

Not being able to communicate.

There are some things that we can't avoid or influence and so it is important to ensure that we have things in our life that maintain our well-being.

Below is a list of things that parents/carers told us help to maintain the well-being of the person they care for.

Things that can help maintain well-being

- Supporting social connections (online if not in person)
- Time outdoors even if short
- A suitable level of physical activity
- Putting in a structure to each day
- Putting in additional communication support if needed
- Ensuring any changes, however small, are prepared for

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morning							
Afternoon							
Evening							

In the box below are things that people who have Down's syndrome told us help their well-being.

Singing and dancing.

Watching TV, films, shows and musicals.

Listening to music.

Playing games.

Activities (crafting, colouring, painting, quizzes).

Connecting with friends and family and peers.

Being active.

Going out.

Being in the outdoors.

Working.

Having purpose.

Pets.

A good night's sleep.

Talking to people who understand me.

When people close to me are happy.

When to seek external help

We all have days when we don't quite feel right (or even weeks) however when this happens for a prolonged period and starts to impact on our activities, daily life and ability to engage with others, we may need to access some help. If you have concerns, contact your GP to discuss.

Conclusion

Recognising the signs that someone isn't feeling good is about knowing the person and noticing any changes that might be quite subtle. It is important to let other people know the signs to look out for and the support a person might need. It might involve adapting to their needs in the way we communicate and our expectations. People who have Down's syndrome are susceptible to the same difficulties as us all but may need extra support to ensure all aspects of their well-being are considered. Knowing what helps to maintain a person's well-being is equally important and ensuring that these things are built into daily life will help to keep people resourced and resilient at more difficult times.

Communication

One of the important findings that came out of our conversations with parents/carers was the degree to which verbal communication is an indicator of well-being (in those who have verbal communication).

Dysfluency and not talking can be a sign of stress or illness and rather than encouraging the person to verbalise, the most helpful strategy is to put in additional support to enable the person to communicate.

We advocate the use of visuals even when a person has verbal communication, to support them at these times.

When stress or other factors come into play that affect well-being, as well as additional support, the person may need more processing time and fewer demands.

For people who don't have verbal communication, there might be signs that they are not ok such as making choices being more difficult, withdrawal and an unwillingness to communicate.

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



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