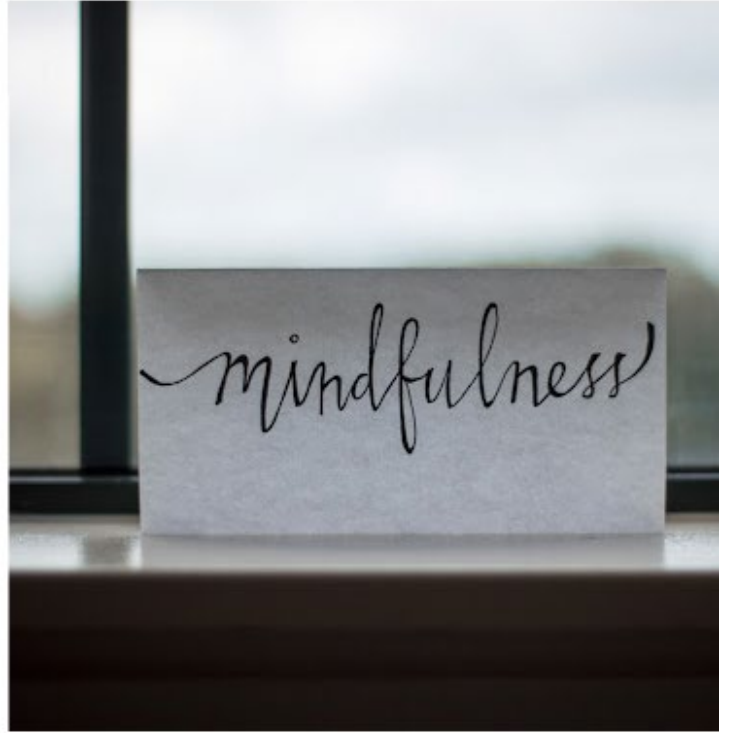


## Emotional well-being



## Parent and carer well-being

## Our resources and Information Team are here to help

Please see our website for up-to-date information: [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)  
If you would like to talk about the activities or where to start, then please get in touch with our helpline by calling 0333 1212 300 or by emailing us on [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk).

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

## What's in this resource?

[What do we mean by well-being?](#)

[Caring for someone and well-being.](#)

[Things that can help.](#)

[Mindfulness.](#)

[Kindness and compassion.](#)

[Resources](#)

## What do we mean by well-being?

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

The NHS identifies five things that promote mental well-being:

- Connection with other people
- Being physically active
- Learning new skills
- Giving to others
- Paying attention to the present

There may be other things that you can add to this list.

We tend to not think about our well-being until we don't feel good, but this booklet is about how we can increase our own well-being in order to resource ourselves as best we can.

## Caring and well-being

### Parenting/caring

Raising a child involves an enormous amount of energy and resources and the parenting role can be idealised. Caring for another is often stressful and the modern world means that families are often living in smaller units away from wider family support and can feel isolated.

You can't  
pour from an  
empty cup



Parenting or caring for a child or adult who has additional needs can bring with it extra challenges that require parents and carers to be much more than caregivers, also requiring expertise in health conditions, behaviour, social care, and education.

### **Caring**

Parents and carers can at times neglect their own health and well-being because of how busy they are thinking about the person they care for. Consequently, the lack of free time means there may not be as much opportunity to do things that are enjoyable and sustain well-being.

Parents and carers may feel guilty when they think about their own needs. However, when we are not resourced, it becomes increasingly difficult to give to another and eventually this can lead to something called burnout.

Burnout is a process that can happen over many years and eventually leads to complete exhaustion. This diagram shows the process of burnout in relation to work; it represents a person's life narrowing so that there is only work. We could replace the word work with caring. As life narrows the symptoms on the right increase and this, in turn, leads to further narrowing.



One way to prevent burnout is to ensure that we do enough things that sustain us and not only things that are draining.

Why not think about the things you do in your life that sustain you and drain you?

We probably still have to do the things on our drainers list, but it is important to get the balance right.

<p style="text-align: center;"><b>Sustainers</b></p> <p style="text-align: center;">Things that give you pleasure and energise you</p>	<p style="text-align: center;"><b>Drainers</b></p> <p style="text-align: center;">Things you don't enjoy and drain you of energy</p>

## Things that can help our well-being

### Sleep

Getting a good night's sleep is essential for our well-being but an area that many people struggle with. If we are caring for someone who has difficulty sleeping, then it can impact on our ability to sleep. It may be that seeking help for the sleep issues of the person you care for is the first step to you getting a good night's sleep.



It is good for everyone to have a routine around bedtime that involves winding down, and sleep meditations and apps can help.

Below are suggestions for positive sleep hygiene by [The Sleep Charity](#):

- As much as possible go to bed and get up at the same time each day.
- Get out into natural light as soon as is practical in the morning, preferably around the same time every day.
- Engage in daytime exercise.
- Avoid stimulants that contain caffeine 8 hours before bedtime.
- Don't go to bed full, hungry or thirsty.
- Reduce electronic use before bedtime and avoid electronic use in the bedroom.
- Don't use alcohol to sleep.
- Avoid nicotine before bed.
- Ensure the bedroom is cool, dark and quiet before bed.
- Ensure that bedroom clocks are not visible.

### Exercise

We don't have to do much exercise to feel the benefits.

Even 20 minutes 3 times a week will have a positive impact on our well-being.

This could be a walk or a run or joining a class online or at a gym.



### Spending time in nature

Being outdoors can have huge benefits to our well-being.

Many people find that introducing a daily walk into their life has a positive impact on well-being.

Being in nature can reduce feelings of isolation and promote calm, reducing our stress hormones and improving our mood.



### Connecting with others

There are different ways to connect with others depending on your circumstances. For some people, seeing family and friends has a very positive impact and is easily accessible.

For others, connection with people who understand is crucial, whether through in person groups or online.

It is important for our well-being to know that we are not alone and that we can reach out to people when we need to.

The DSA has a number of ways that parents and carers can connect, please see the [resources section](#) for these.



### Gratitude

Gratitude is the quality of being thankful. It focuses our attention on the positive things in our life (as we tend to naturally dwell on the negative).

We can be grateful for everyday things such as water, a roof over our head, friends or the food we eat as well as little things that happen on a daily basis. We can be grateful for small acts of kindness that we may otherwise take for granted.

## Daily gratitude practices

One suggestion is to have a gratitude journal in which you can write down 3 things that you are grateful for in your day, perhaps before going to bed.

It can be anything but if that feels too difficult you can use the following to guide you:

- A person or animal
- An experience
- An object



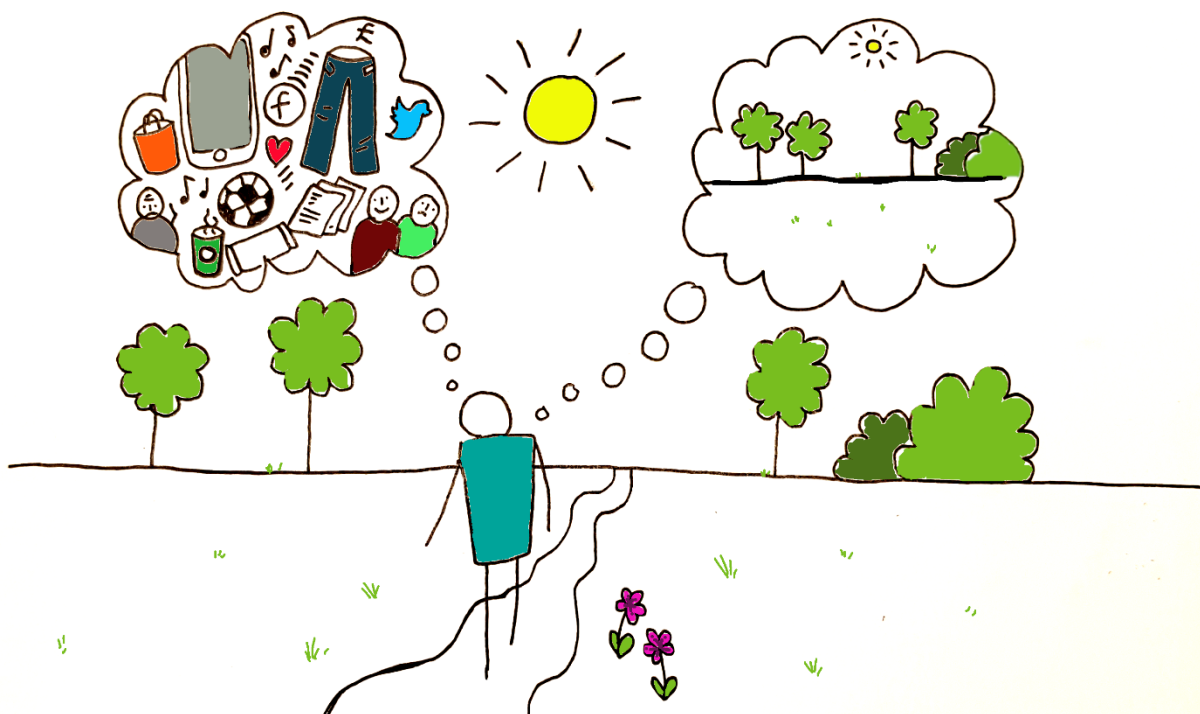
## Mindfulness

When we are busy and the to do list is never ending it can be hard to stop and rest and appreciate our life.

### Autopilot

Apparently, we spend nearly 50% of our time in what is known as autopilot which means we are often unconscious of what we do and our decision-making. This can be helpful in performing routine tasks as it prevents us from overloading. However, when the balance tips into us spending a lot of our life this way we can become dis-engaged from our day-to-day experience. If we have a tendency towards worrying when we are operating on autopilot our mind is free to wander, often repeating unhelpful negative thoughts.

Mindfulness is the opposite of autopilot and is being fully present with our whole experience moment by moment. This includes thoughts, emotions, body sensations and other sensory input. This awareness is without judgment and can take some practice!





## Doing and being

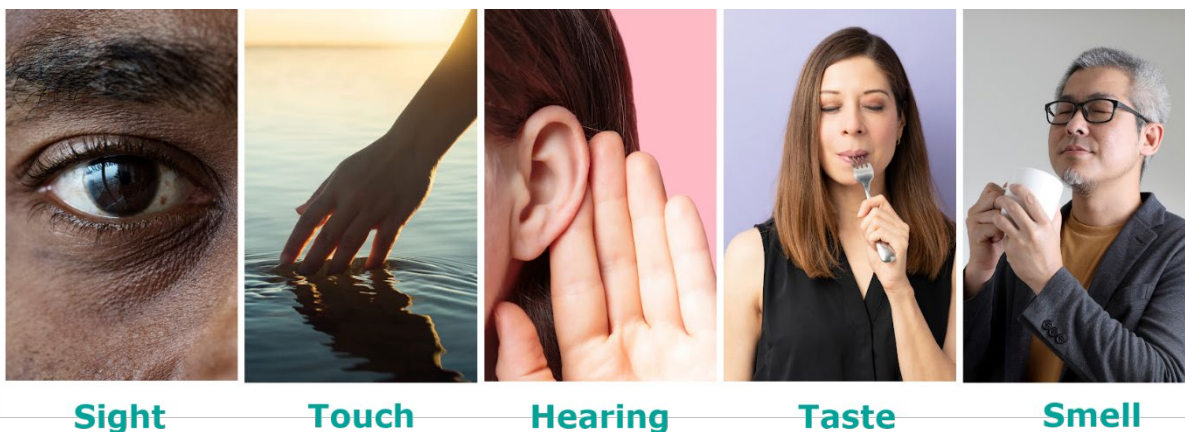
We live in a culture that is very focused on doing. It is almost embarrassing to say that we are not busy and being busy can be seen as a badge of honour.

Even when we are not doing something our mind can stay in the doing mode, planning the future or going over things that have happened. It is important that we rest our mind and body to give it a break. The opposite of doing is 'being' which means being mindful and fully present with our mind/body and this helps with creativity and seeing different perspectives.

Professor Mark Williams, a leading Mindfulness researcher and teacher talks about how we have a Verbal/Conceptual mode of mind and a Sensory/Perceptual mode. The more stressed we are the more we conceptualise; we try to think our way out of stress when in fact the way to reduce stress is to move into sensory/perceptual mode.

We do this by engaging more with our senses. We do so by seeing, hearing, smelling, touching, tasting, and also feeling. When we drink a cup of tea we savour it, when we eat our dinner, we really smell it, see it and taste it and when we go for a walk, we really notice our surroundings and our body moving.

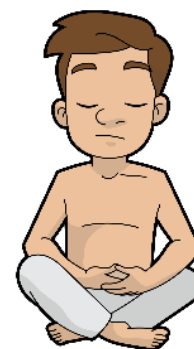
We can then slightly detach and even watch our thoughts rather than be lost in thinking and engage with our direct experience of being.



## Meditation and other Mindfulness practices

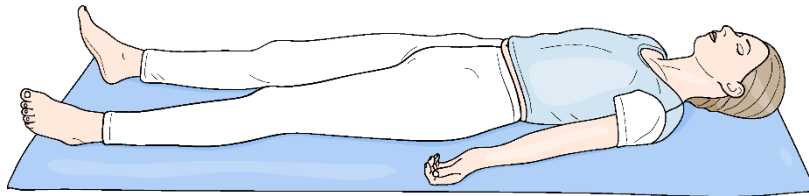
Meditation is a way we can help to calm and quieten the mind. Many people think they cannot meditate because they cannot clear their mind however meditation is not about clearing our mind but calming the mind and developing the ability to observe our experience without judgment.

We might use the breath as an anchor to keep coming back to. We will notice thoughts, sounds etc. but we make a choice to come back to feeling the breath. When we do this, we are interested and curious, we try not to judge our experience.



### Some common Mindfulness practices

- A **Body Scan** is when we shift our attention around the body starting with either the head or the feet and notice the sensations and whether we feel them as pleasant, unpleasant or neutral.
- 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 focused 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. The intention is to be present with the sensations of the movement rather than focusing on the outcome. Yoga and Qigong are mindful movement practices.



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 soapy water on our hands as we clean each item with full attention
- **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:** We might sit and listen to sounds, noticing the sensory quality or give someone our full attention when they are talking rather than planning what we are going to say or attending to other things
- **Seeing:** we might spend time looking at nature, or inside at our environment, taking in colour, shapes and textures..

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 (see resource list).



## Kindness and compassion

### Being 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 acted better' and we become our own worst critic.

We are allowed to make mistakes – we are 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 more rubbish than we already do. Self-kindness involves being accepting of our mistakes and imperfections and talking to ourselves with a kind voice, perhaps in a similar way to 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.



### Self-compassion

With self-compassion we move from 'this is really difficult right now,' to 'how can I comfort and care for myself in this moment?'

Kristen Neff talks about how there are three elements to self-compassion and that we move from bringing kindness to ourselves to acknowledging that others are also going through this. Finally, we bring mindfulness to our experience which means that we are able to hold our suffering while acknowledging that there are also good things, things that are going well.

### 3 elements of self-compassion

**Self-kindness:**  
Understanding  
not punishment

**Sense of  
common  
humanity:**  
Everybody goes  
through this

**Mindfulness:**  
Neither ignoring  
nor exaggerating  
feelings of failure

Kristen Neff

Some ideas for self-compassion practices

- Taking a self-compassion break
- Write a letter to yourself as if you are your own best friend offering acceptance, kindness and care to your experience
- Self-soothing through touch (hand on heart)
- Doing something for yourself each day

## Resources

### Down's Syndrome Association

Connecting with others is a key component of well-being and particularly connecting with those who understand what our life is like.

The DSA has a number of ways that you can connect with other parents and carers.

There are these interactive sessions:

- The Parent/Carer Complex Needs group
- Well-being Wednesday (every fortnight – see below)
- Sharing Positive Support (every fortnight)

Our Helpline team (0333 1212 300, Monday to Friday, 10am-4pm) are there to provide a listening ear and advice.

### Well-being Wednesdays

The DSA now runs a regular well-being session for parents/carers held fortnightly on a Wednesday morning 10:30am – 11:30am.

The sessions involve a chance to check in with other parents/carers and include guided Mindfulness/relaxation practices.

The sessions are participatory and interactive and so it will be of benefit if you are able to join with both your camera and audio on. However, there may be times when you don't feel able to do so which is ok.

### Other websites

NHS Well-being: [nhs.uk/mental-health/self-help/guides-tools-and-activities/five-steps-to-mental-wellbeing/](https://www.nhs.uk/mental-health/self-help/guides-tools-and-activities/five-steps-to-mental-wellbeing/)

NHS Mindfulness: [nhs.uk/mental-health/self-help/guides-tools-and-activities/five-steps-to-mental-wellbeing/](https://www.nhs.uk/mental-health/self-help/guides-tools-and-activities/five-steps-to-mental-wellbeing/)

Self-compassion (Dr Kristen Neff): [self-compassion.org/](https://www.self-compassion.org/)



Action for Happiness: [actionforhappiness.org/](http://actionforhappiness.org/)

The action for happiness website has lots of helpful resources including monthly calendars with activities which the whole family can do.

### Apps

If you would like to try mindfulness, then downloading an app can be helpful. Here are some examples:

[Headspace](#)

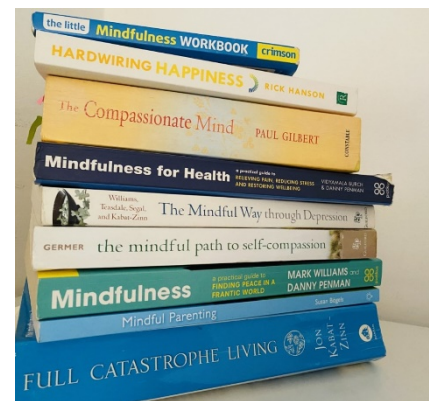
[Insight Timer](#)

[Calm](#)

### Mindfulness books

Here is a selection of mindfulness books:

- *The Little Mindfulness Workbook* by Gary Hennessey  
If you would like to work through an eight-week course *The Little Mindfulness Workbook* is a great place to start
- *Hardwiring Happiness* by Rick Hanson
- *The Compassionate Mind* by Paul Gilbert
- *Mindfulness for Health: A practical guide to relieving pain, reducing stress and restoring wellbeing* by Vidyamala Burch and Dr Danny Penman
- *The Mindful Way through Depression: Freeing Yourself from Chronic Unhappiness* by J. Mark G. Williams, John D. Teasdale, Zindel V. Segal, Jon Kabat-Zinn
- *The Mindful Path to Self-Compassion* by Christopher Germer
- *Mindfulness: A practical guide to finding peace in a frantic world* by Prof Mark Williams
- *Mindful Parenting: Finding Space To Be – In a World of To Do* by Susan Bögels
- *Full Catastrophe Living, Revised Edition: How to cope with stress, pain and illness using mindfulness meditation* by Jon Kabat-Zinn



### Other

If you would like to do a mindfulness course you can look for a teacher on the British Association of Mindfulness-based Approaches (BAMBA) website: [bamba.org.uk](http://bamba.org.uk)

## References

This booklet was compiled by Jane Mitchell, Specialist Advisor to the Down's Syndrome.

Jane is an accredited Mindfulness teacher with [Breathworks](#) and some of the content is taken from the courses she runs and her own teaching.

Other information in this booklet was taken from a wide range of sources including:

- NHS website
- Dr. Kristen Neff's work on Self-Compassion
- Dr. Rick Hanson's work on hardwiring happiness
- Prof. Mark Williams' work on Mindfulness Based Cognitive Therapy
- The Little Mindfulness Workbook by Gary Hennessy
- The Sleep Charity website
- Action for Happiness website

(links to websites are in the body of the document)

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

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[www.dsactive.org](http://www.dsactive.org)



[www.langdondownmuseum.org.uk](http://www.langdondownmuseum.org.uk)



[www.langdondowncentre.org.uk](http://www.langdondowncentre.org.uk)



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