

Factsheet 05

Compassion Fatigue



Warning

Some information on this page may be difficult to read or may cause strong or upsetting feelings. Please only carry on reading if you feel safe to do so.

Compassion Fatigue can particularly impact those caring for an individual with a rare condition, a chronic health condition or disability.

- 1 in 5 or roughly 5.8 -10.6 million people are unpaid carers in the UK adults care for others (State of Caring Report 2025: Carers UK).
- This equates to around 63 million reported unpaid carers worldwide. However, due to the amount of carers not registered it is thought that this number is around 2 billion people globally.
- The International Labour Organisation estimated that 748 million people were not able to enter into the labour force as a result of their caring responsibilities (most of these were women).
- 68% of carers stated that they needed health and wellbeing support (State of Caring Report 2025: Carers UK).

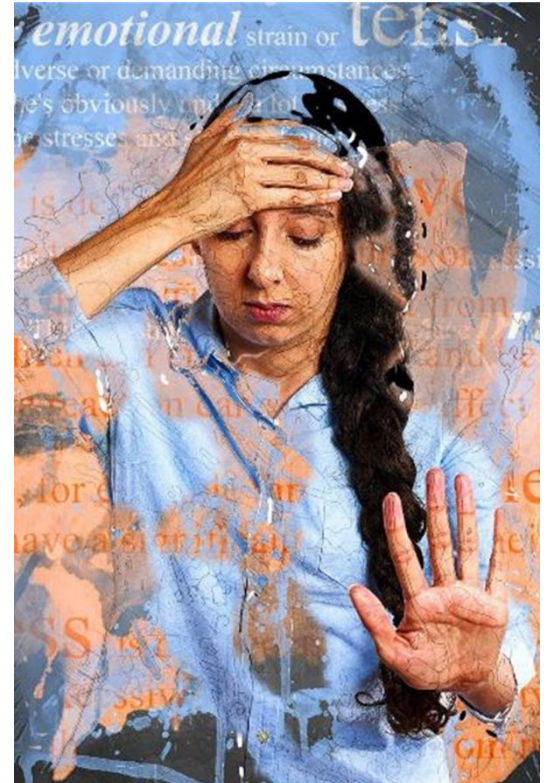


Compassion Fatigue can be described as:

- A state of exhaustion; physical, emotional and psychological caused by caring for others.

Signs and symptoms can include:

- Withdrawal
- Rejection
- Emotional disconnection
- Feeling emotionally exhausted
- Feeling overly emotional
- Headaches, stomach aches or muscle aches
- Loss of appetite or overeating
- Having trouble sleeping, or being constantly tired
- Feeling irritable or angry
- Suffering mood swings
- Becoming forgetful or less productive
- Becoming pessimistic or cynical
- Struggling to make crucial decisions
- Feeling isolated
- Feeling overly anxious or depressed
- Experiencing addiction
- Catching colds or the flu more regularly
- Feeling numb or detached



The Cycle of Compassion Fatigue:

You may not experience each stage of this cycle or experience things in a different order. What's important to remember is that these feelings will pass. However, sometimes it takes seeking support to help you manage these thoughts, feelings and emotions.

- **The caring stage**

When you feel increased feelings of wanting to care for people and neglect yourself. Associated with the feeling of guilt. You might be saying to yourself: "I'm not doing enough". You could form unhealthy habits such as skipping meals for example.

➤ **The stage of stagnation**

You may feel that your efforts aren't making any difference. You feel frustrated and disillusioned. You may also feel grief at this stage.

➤ **The frustration stage**

You may feel anxious, angry, resentful or overwhelmed. Physical signs may include headaches, insomnia and fatigue.

➤ **The stage of apathy**

You may feel emotionally numb or detached from your work, friends or family and the people/person you are supporting.

Grief & Loss

Why Grief Matters in Alström Syndrome

Grief is a deeply personal experience, and for those affected by Alström Syndrome it can take many forms. Whether you are coming to terms with a diagnosis, adjusting to sight or hearing loss, or mourning the loss of a loved one, grief can be a big part of the journey.

At Alström Syndrome UK, we understand that loss isn't just about bereavement. It can also mean grieving for the things that have changed, our abilities, our independence, or the future we once imagined. These feelings are real and valid, and you don't have to face them alone.

This section is here to offer support, resources, and reassurance that whatever you are feeling, it is okay.

Types of Grief You May Experience

Anticipatory Grief

Sometimes, grief begins before a loss happens. Knowing that Alström Syndrome is a life-limiting condition can bring feelings of sadness, worry, or fear for the future. This is called anticipatory grief, and it is completely natural.

Loss of Abilities

Changes in sight, hearing, or health can feel like losing a part of yourself. It's okay to grieve these changes. Finding new ways to adapt and seeking support from others who understand can help.

Unspoken Grief

Grief isn't always about losing a person. It can also be about the life we hoped for—the career we dreamed of, the experiences we longed for, or the independence we once had. These silent losses are just as real, and they deserve space to be acknowledged.

How to Cope with Grief

- **Acknowledge Your Feelings**
There is no right way to grieve. However, you feel, angry, numb, heartbroken, or even relieved, it's okay.
- **Talk to Someone**
You don't have to go through this alone. Whether it's a friend, family member, therapist, or support group, sharing your grief can help lighten the load.
- **Find Comfort in Routine**
Small familiar actions like making a cup of tea, listening to music, or going for a short walk can bring a sense of stability.
- **Allow Yourself to Rest**
Grief is exhausting, both physically and emotionally. Be kind to yourself and take the time you need.

Where to Find Support

Emotional & Bereavement Support

- Cruse Bereavement Support.
Free helpline, chat, and local grief support.
www.cruse.org.uk
- Marie Curie Bereavement Support.
Support for those grieving due to terminal illness.
www.mariecurie.org.uk
- At a Loss.
A directory of grief support services.
www.ataloss.org

Support for Sight & Hearing Loss

- RNIB Counselling & Emotional Support.
Help for those adjusting to vision loss.
www.rnib.org.uk
- Sense UK
Support for people with combined sight and hearing loss.
www.sense.org.uk

Support for Families & Young People

- Winston's Wish.
Support for children and young people facing bereavement.
www.winstonswish.org
- The Compassionate Friends.
Peer support for parents who have lost a child.
www.tcf.org.uk

Grief is a journey, not a destination.

Books & Guides

- "Living with Loss" by Liz McNeill Taylor.
Gentle guidance on different types of loss.
- "Healing After Loss" by Martha Whitmore Hickman.
Daily readings on grief.
- "Beyond Words: Grieving When Your Loved One Has Dementia"
by Carol B. Amos.
Though dementia-focused, it helps with loss while someone is still present.

Burn Out

Individuals who have Alström Syndrome may be more likely to experience burn out due to their exposure to continuous change due to their condition(s), numerous trips, treatments and appointments at hospital and other elements in their life such as school, work or other commitments.

Burn out can be described as:

- When an individual reaches a point of physical and emotional exhaustion.
- This can happen when an individual is exposed to ongoing stressful situations.
- It doesn't go away on its own and can get worse if the underlying issues aren't addressed.
- If ignored burn out can have significant implications for your physical and mental health.

Signs and Symptoms of Burn Out

- Feeling tired or drained most of the time.
- Feeling helpless, trapped or defeated.
- Feeling detached or alone in the world.
- Having a cynical or negative outlook.
- Self-doubt.
- Procrastinating or taking longer to get things done.
- Feeling overwhelmed.

The Importance of Self-Care:

- Asking for help might sometimes feel like failure but this is NOT the case.
- You may have been conditioned to take care of other persons needs before your own.
- Watching someone you care about struggle can be emotionally draining
- You can sometimes feel guilty because you don't see the situation improving but this is NOT your fault.
- BE KIND TO YOURSELF and try to communicate what you need in order to help create healthy boundaries for yourself and others.
- Key difference is the motive behind the action.
- When you are selfish you often forget the needs of other people and focus on what is best for yourself.
- Self-care is where you take time to invest your energy in something that nourishes your soul and spirit
- Time to look after yourself.

- Balancing your work/ home/ personal commitments and focusing on your own wellbeing.
- Self-care can be hard, but it is essential. As the saying goes “you can’t pour from an empty cup” so refilling your cup means that you can support your loved ones better once you support yourself.

Self-Care Activities & Helpful Strategies

- Meditation
- Mindfulness
- Alone time
- Baking/ cooking
- Reading
- Listening to music
- Beauty appointment
- Taking a bath
- Date night (with a friend, family member, partner or spouse)
- Colouring/ painting
- Knitting and other textile activities
- Journaling or creative writing
- Singing
- Dancing
- Take off your Hats. Sometimes it can help you to do this if you actually imagine what the hats look like and imagine a different one for each role you have
- Know your body
- Take time for Self-Care - when you lead a busy life this can be difficult to find the balance. Try to build it into your daily routine. Just for a minute to start off with then gradually increase it.
- Set reasonable boundaries
- Practice Mindfulness
- Take breaks
- Ask for support
- Look for support groups
- Find some fun time for you and the person you care for
- Take respite
- Start journal writing
- Enjoy a hobby



- Speak to a therapist
- Speak to your manager at work
- Embrace their independence
- Treat yourself like you're your own best friend- studies show that people find it easier to be kind to someone else than ourselves. We can sometimes be overly critical. Talk to and treat yourself as if you're some-one you like. What would you say to them? How would you want them to treat themselves?



Sensory Overload

This condition can be described as the overstimulation of 1 or more of the bodies 5 senses. This is when the brain struggles to interpret, prioritise or otherwise process sensory inputs. The brain then communicates to the body that it is time to escape the sensory input. These messages can cause an individual to experience feelings of discomfort and panic.



- 1 in 6 children experience sensory overload. It is thought that this is because the child's mind is still developing.

Some conditions that are associated with sensory overload are:

- Autism- for people affected, process sounds differently.
- ADHD- as sensory inputs compete from attention in the brain.
- PTSD- people can become hypersensitive to their surroundings. Overload happens when a person is reminded of their trauma because of specific sensory triggers.
- Sensory Processing Disorder- a neurological disorder that occurs when a person finds it difficult to respond to sensory input. A person can be sensitive to smell, touch or taste or sensitive to certain pressures so looks for greater stimulation through touch.
- Chronic Fatigue Syndrome.
- Fibromyalgia.
- Multiple sclerosis MS.

Signs & Symptoms of Sensory Overload

Symptoms can vary from person to person as every individual's triggers are different. However, some common signs to look out for are:

- An inability to ignore; loud sounds, strong smells or other kinds of sensory input
- A sense of discomfort
- Anxiety & fear
- Extreme sensitivity to certain clothes or other textures
- Feeling overwhelmed or agitated
- Irritability
- Loss of focus
- Restlessness
- Stress
- Insomnia
- Paralyzing confusion
- Racing or intrusive thoughts
- Dizziness
- A flushed, red face
- Shaking or trembling
- Sweating
- Tightness in your chest

Signs in children

- Anxiety, irritability and restlessness
- Avoiding specific places or situations
- Closing the eyes
- Covering the face
- Crying
- Placing their hands over their ears
- The inability to converse with others or connect with them
- Running away from specific places or situations



Coping Strategies

There is no specific treatment for those who experience sensory overload. It is about planning and enabling individuals to be able to manage their reactions.

Some things that might help are:

- See an Occupational Therapist as they may be able to suggest changes to environment which may reduce triggers
- Keep a diary of signs, symptoms and triggers for sensory overload, identify and record your triggers
- Practice your coping strategies
- Avoid situations that may trigger the overload such as loud places or flashing lights
- Asking others to limit sensory input - this could be keeping noise to a minimum or turning down bright lights
- Identify safe places at home/ school/ work that an individual can retreat to when they feel overloaded
- Staying near an exit at a party or concert so that it's easy to leave quickly if necessary
- Talking to friends/ teachers/ colleagues/ family members and gaining their support in limiting sensory input
- Taking regular breaks- making sure that you get enough rest and sleep
- Drinking lots of water and eating a balanced diet
- Give your child the words to explain how they feel and what is happening to them
- Validate the child's feelings and experiences

- Deep breathing and using the 4 x4 box breathing technique
These techniques can be found on the ASUK website:
<https://www.alstrom.org.uk/wellbeing-service/#practical-techniques>
- Practicing meditation
- Using guided imagery



We are here for you.

Alström Syndrome UK offer a wellbeing service for those diagnosed with Alström Syndrome and their families.

Please feel free to get in touch with our Wellbeing Coordinator, Melissa Crowland who can discuss ways she can support you on your journey.

Email: Melissa on melissa.crowland@alstrom.org.uk

Telephone: Melissa on 07301078059

Please note that Melissa works part-time on a Wednesday and Friday.

All our wellbeing resources, including recorded webinars, factsheets, strategies and techniques can be found on our wellbeing page on the ASUK website

<https://www.alstrom.org.uk/wellbeing-service/>

