A fact sheet about

What alexithymia is

UnderstandingZoe

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What alexithymia is

What alexithymia is, who has it, and another way to share how you are.



Key points

- Alexithymia means finding it hard to notice, name and describe your own feelings (definition below).
- It is not the same as having no feelings. Often a person knows they feel something, but not which feeling it is.
- About half of autistic people have it, and many do not. There is much less research with ADHD adults.
- It may help to tell the people around you, and to agree on another way to share, such as saying what you need.

What alexithymia is

Someone asks how you feel about a change of plan, and you have no answer. You know something is going on, because your chest is tight and you want to leave the room. But you cannot tell if it is worry, anger or something else. Then you come across the word alexithymia, and you wonder what it means and if it fits you.

Alexithymia means finding it hard to notice, name and describe your own feelings. It is the name used in research, and it can sound clinical. But it describes a difference in how feelings get noticed and named, not something missing in you.

It is not the same as having no feelings. A person may know that they feel something, but not know if it is sadness, anger or fear. Some people also find it hard to tell a feeling apart from a body state, like hunger or being too hot.

It comes in degrees, and it is different for each person. Some people find it hard now and then, and some find it hard most of the time: it is about how your own feelings reach you and how you put them into words. You can read more about how body signals shape your feelings here.

Who has it, and what it does not mean

Studies suggest that about half of autistic people have alexithymia. In the same studies, it was found in about 1 in 20 people who were not autistic. So it is common in autistic people, but it is not part of being autistic. Many autistic people notice and name their feelings with ease, and some people who are not autistic find it very hard.

Research suggests that, where a person does find feelings hard to read, alexithymia explains it better than being autistic does.

And if you are ADHD or neurodivergent in another way, you may recognise this too.

More broadly, research on autism, ADHD and neurodivergence has often left out BBIA (Black, Brown, Indigenous and Asian) people, LGBTQIA+ people and other marginalised groups. Your lived experience is what is most valid.

The one thing to try: let people know naming feelings is hard for you, and agree another way to share

Many everyday moments ask you to name a feeling: "how are you?", a hard talk at home, or a GP asking about your mood. If naming feelings is hard for you, you do not have to keep answering in the way you are asked. You can tell people, and agree on a way to share that suits you.

Choose one person, such as a parent, sibling, partner, friend, support worker or your GP. Tell them that naming feelings is hard for you, and that another way works better. Then agree one way to share:

- say what you need, not what you feel: "I need quiet" or "I need food"
- use a colour or a word from a short list, like "a grey day"
- point to a written list or a set of pictures
- use a signal you agreed on earlier, like a hand sign or one emoji
- write it down later, once you have had some time

Neurodivergent adults have said that health care goes better when doctors and other health workers accept the way they need to communicate. That includes writing things down. In one study, autistic adults with more alexithymia found it harder to use support that asks you to name and question your thoughts and feelings. Other kinds of support, such as breathing or relaxation, were no harder for them. So it is fair to ask for help that does not rest on naming feelings.

You can keep your needs list or your colour words in your notes in the Understanding Zoe app. Then you can show the screen when someone asks, or share it with them, with no need to speak.

This step comes from what neurodivergent adults say helps them. It has not been tested in research yet, so it is anchored in lived experience and in what the community shares about it. And lived experience is valid too.

People may forget at first, so you may need to remind them. To work out what a feeling might be, you can read more about using the clues around it here.

Getting support

This page describes what many adults say about themselves. It is not an assessment, and it cannot tell you what is going on for you.

You can ask for support at any point. A GP is a good place to start. A GP can talk with you about a Mental Health Treatment Plan, which can lower the cost of sessions. Different health professionals can help you find ways to notice and share your feelings that suit you, and your GP can help you work out who is right for you.

You can also book a telehealth session through Understanding Zoe.

It can help to say at the start that naming feelings is hard for you. You can bring your list from the app, or a support person who knows you well, to help you share what is going on.

Sources

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UnderstandingZoe

Understanding Zoe is the first neuroaffirming AI-powered app that turns every report, observation and moment into an actionable next step, supporting neurodivergent people and those who care about them to thrive.

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