

Grief, loss and Autistic people

Information and support for Autistic adults and the people who love them

Kent and Medway

About this guide

This guide is for Autistic adults who are facing the serious illness or death of someone they love, and for the family and friends around them.

It explains how grief can look different for Autistic people, shares practical ideas that can help, and lists local and national support.

You do not need to read it all at once. You can go straight to the parts that are useful to you right now.

How this guide is organised

- **Part 1:** Grief can look different
- **Part 2:** How family and friends can help
- **Part 3:** For Autistic adults: your way of grieving is valid
- **Part 4:** Support for partners, parents and carers
- **Part 5:** Where to get support (local and national)
- **Part 6:** If things become too much
- **Part 7:** Words explained

A note on words. We say "Autistic person" rather than "person with autism", because many Autistic people see being Autistic as part of who they are (not something separate from them). We use a capital "A" because being Autistic is also a cultural identity and community.

Part 1: Grief can look different

When someone we love is dying, people often expect grief to look a certain way: crying, talking about feelings, wanting to be close to others. Many Autistic people

grieve deeply, but in ways that others do not always recognise. This can lead to painful misunderstandings at a time when everyone is already hurting.

Simply put

It may look like nothing is happening. That does not mean nothing is happening.

Things you might notice

- **Carrying on as normal.** Keeping to routines, work or dedicated interests can be how an Autistic person stays steady when everything else feels uncertain. It is not a sign that they do not care.
- **Delayed reactions.** Taking in big news can take days, weeks or months. Feelings may arrive later, sometimes suddenly, and sometimes only after the death rather than before it.
- **Not wanting to talk about it.** Talking about feelings face to face can be overwhelming. Some people find it easier to write, text, or talk while doing something else side by side.
- **Focusing on facts and details.** Asking very practical or detailed questions (about medication, the hospice, or what happens next) can be a way of making sense of things.
- **Finding it hard to name feelings.** Some Autistic people find it difficult to notice or name emotions in their body. Grief may show up as tiredness, headaches, stomach problems, sensory overload, not eating or not sleeping, rather than as "sadness".
- **Shutdown or meltdown.** When things become too much, a person may go very quiet and withdraw (shutdown) or become very distressed (meltdown). These are responses to overwhelm, not "bad behaviour".
- **More stimming.** Rocking, pacing, fidgeting, humming or repeating words may increase. This is self-soothing, and it helps (unless it becomes harmful).
- **Masking becoming harder.** Many Autistic adults have spent years suppressing their natural responses to avoid negative reactions from others. Under the stress of grief, keeping this "mask" up can become exhausting, or can stop working altogether.

Why routine matters so much

Many Autistic people have a **monotropic** way of thinking. This means attention flows deeply into one or a few things at a time, rather than being spread across many.

When life feels frightening and unpredictable, staying in a familiar channel (a routine, work, a dedicated interest) can protect a person from being overwhelmed. Pulling someone away from it to "face things" can make processing harder, not easier.

Grief can start before someone dies

Grief often begins while someone is still alive but seriously ill. This is called anticipatory grief.

Everyone in a family may be grieving at the same time, in very different ways. It is common for people to misread each other: one person may seem "too upset", another may seem "not bothered at all". Often, both are struggling.

Part 2: How family and friends can help

There is no need to force a conversation. The aim is to keep the door open, share clear information, and let the Autistic person choose how and when they take part.

Ten ideas that often help

1. **Offer, do not insist.** Let them know you are there, without needing a reply.
2. **Use the way they prefer to communicate.** This might be text, email, a shared note, a voice message, or talking side by side (on a walk, in the car, while cooking).
3. **Be clear and honest.** Gentle phrases like "slipping away" or "passing" can be confusing. Clear words, such as "Dad is dying. The nurses think it may be weeks, not months", can feel hard to say, but are often easier to understand. Kind and clear can go together.
4. **Put information in writing too,** so it can be read again when they are ready.
5. **Give warning of changes.** For example: hospice or nurse visits, equipment arriving at home, visitors, what might happen near the end, and plans for the funeral. Knowing what to expect reduces overwhelm.

6. **Offer real choices.** Whether to visit, for how long, and with whom. What they might like to do or say: a letter, a photo, a recording, or just sitting quietly. They can change their mind.
7. **Protect routines and sensory needs.** Familiar food, regular mealtimes, a quiet space, headphones, and time alone.
8. **Respect dedicated interests.** These are not a distraction from grief; they can be a bridge to it (making something, sharing a memory, creating a playlist).
9. **Keep checking in over time.** Feelings may come much later, including months after a death. Support is still needed then.
10. **Look after yourself too.** You cannot pour from an empty cup. See Part 4.

An example message

"I know a lot is happening with Dad at the moment. You don't need to reply or talk about it unless you want to. If you ever want to know what the nurses have said, I can write it down for you. I'm glad you're keeping your routine going. Would you like dinner in your room tonight, or with me?"

A message like this shares care without demanding a response, offers information on their terms, and gives a simple, low-pressure choice.

What helps, and what can make it harder

Things that may help	Things that may make it harder
Time and space to process	Pressure to talk or react "right now"
Clear, plain words	Hints, euphemisms or unfinished sentences
Written information to read again	Big news given suddenly, or in a busy place
Choices about visiting and taking part	Being told they "should" visit, cry or say goodbye
Keeping routines where possible	Taking routines away to "make them face it"

Things that may help	Things that may make it harder
Quiet, low-sensory spaces	Crowded rooms, strong smells, lots of hugging or touch
Noticing care shown in their own way	Calling them cold, selfish or "in denial"

Gently watching for signs of distress

Autistic people may not say out loud that they are struggling. It can help to notice, quietly, if someone stops eating or sleeping, stops doing things they usually enjoy, withdraws much more than usual, or talks about not wanting to be here.

If you are worried, it is OK to ask directly and kindly (for example, by text). Asking about suicide does not put the idea in someone's head. Part 6 lists where to get help quickly.

Part 3: For Autistic adults: your way of grieving is valid

If you are Autistic and someone you love is seriously ill, or has died, you might feel lots of things, or nothing yet, or feelings that do not have names. All of this is OK. There is no right way to grieve.

Things that might help you

- **Keep your routines if they help.** Staying steady is not the same as not caring.
- **Tell people what works for you.** Even a short text can help, such as: "I can't talk about it, but please send me updates by text."
- **Ask for the information you need.** You are allowed to want facts, details, and things written down.
- **Take breaks.** It is OK to step away from people, noise and busy places.
- **Look after your body.** Grief can make it harder to notice hunger, thirst or tiredness. Setting reminders to eat, drink and rest can help.
- **Use tools that suit you.** A journal, a visual timeline, sensory items, music, drawing, or making something in memory of your loved one.
- **You can choose how to say goodbye.** You might visit, or you might not. You could write a letter, record a message, or choose something to leave in their room. You can change your mind.

- **Find people who get it.** Autistic peer groups can be a place where you do not have to explain yourself (see Part 5).
- **If feelings arrive later, that is normal.** Support is still there weeks, months or years later.

You deserve support that respects who you are

If you are non-binary, trans or LGBTQ+, you deserve support that uses your name and pronouns and respects your identity, alongside your Autistic needs. You can ask any service how they will do this. There are LGBTQ+ services listed in Part 5.

You also have a right to reasonable adjustments from NHS and care services. For example: written information, extra time, a quiet waiting space, clear questions, or appointments by text, email or video.

Part 4: Support for partners, parents and carers

If you are caring for someone who is dying, and also worried about an Autistic family member, you are holding a great deal. Your own grief matters too.

- **Ask for a Carer's Assessment.** This is free. It is about your wellbeing, not a test of how well you are coping, and you can ask for one even if the person you care for does not get support from the council.
- **Talk to the hospice or nursing team.** If your loved one is known to a hospice, family counselling is usually available before and after a death. You can also ask them for advice about supporting an Autistic family member.
- **Find your own space to talk.** Carers' groups, a counsellor, a trusted friend, or a helpline.
- **Carry a Carers' Emergency Card.** Kent and Medway run a scheme so that, if you become unwell or have an accident, someone can be contacted to support the person you care for.
- **You do not have to fix this.** Your Autistic family member may be processing in their own way and at their own pace. Keeping the door open is enough.

Part 5: Where to get support

Support specifically for Autistic grief is still rare. Most people find what they need by combining bereavement services with Autistic and neurodivergent-led spaces. Services change, so please check details before relying on them.

Autistic and neurodivergent-led support

Service	What they offer	How to get in touch
STAK.life (Stefan's Acts of Kindness) CIC	A neurodivergent-led, neuro-affirming not-for-profit based in Thanet, founded by Emma and Tristan Kluibenschadl in memory of their son Stefan. Offers creative and wellbeing support groups for neurodivergent young people and for people experiencing grief and loss, including creative programmes of eight sessions for people living with complex grief. Also runs workshops for neurodivergent people exploring their "neuro-self", and training for families and professionals. <i>Please check with them which groups are open to adults and to people living outside Thanet.</i>	Website: www.stak.life Use the contact form on the website, or sign up for their updates about groups and workshops.
All Together Autistic (Advocacy for All)	Peer support groups (in person and online) across Kent and Medway, run by Autistic peer supporters and advocates. For Autistic adults (18+) without a diagnosed learning disability, who are diagnosed or on the waiting list, and who can attend without one-to-one support.	Email: SEAS@advocacyforall.org.uk Phone: 07548 829619 Website: advocacyforall.org.uk

Service	What they offer	How to get in touch
Adult Autistic Support Service (Kent Community Health NHS Foundation Trust)	Keyworkers, peer support workers (with lived experience) and practitioners offering psychoeducation workshops, including on emotional regulation, interoception, and transition and change. Some people are also offered up to 12 weeks of one-to-one support. For Autistic adults with a diagnosis and a GP in Kent or Medway. Referral must come from a health or social care professional (for example, a GP).	Advice line: 0300 790 0511 Monday 1pm to 4pm, Wednesday and Friday 9am to 1pm (no voicemail). Family members and carers can call too.
Other East Kent peer groups	Including ND Harbour peer groups in Canterbury (with a weekly group for Autistic adults), East Kent Autism and ADHD Social, and Neurodivergent Friends in Thanet.	Listed at: ndkentandmedway.co.uk (Adults, then Local support)
Shepway Autism Support Group	A local support group in the Folkestone and Hythe area, mainly known for supporting families. Contact them to check whether their groups suit families of Autistic adults.	Search "Shepway Autism Support Group" online

Hospice, end-of-life and bereavement support

Service	What they offer	How to get in touch
Pilgrims Hospices (covers east Kent, including Folkestone and Hythe)	Free counselling for family, friends and unpaid carers of hospice patients, both before and after a death. Counsellors can also advise on supporting other family members. Stepping Stones bereavement support is open to any bereaved adult in east Kent: bereavement cafés, walk and talk groups, and a drop-in peer group. Up to six sessions of bereavement counselling are available for family and friends of hospice patients.	24-hour advice line (patients, families and carers): 01233 504 133 This is not a crisis line. Bereavement support: 01233 504 127 (option 2) Website: pilgrimshospices.org
Cruse Bereavement Support	National bereavement charity with a free helpline, local services, and a helpful page on neurodiversity and grief (search "Cruse neurodiversity and grief").	Helpline: 0808 808 1677 Website: cruse.org.uk

Service	What they offer	How to get in touch
Marie Curie Support Line	Information and emotional support for anyone affected by terminal illness, including family members and carers.	Phone: 0800 090 2309 Website: mariecurie.org.uk
Elsewhere in Kent and Medway	Heart of Kent Hospice (Maidstone area) and Wisdom Hospice (Medway) also offer family and carer support.	hokh.org and medwaycommunityhealthcare.nhs.uk

Support for carers

Service	What they offer	How to get in touch
Carers' Support East Kent	Information, a listening ear, drop-ins, support groups and an online carers' forum for carers in Ashford, Canterbury, Dover, Faversham, Folkestone and Hythe, and Thanet. Carries out Carer's Needs Assessments on behalf of Kent County Council.	Website: carersek.org.uk
Kent County Council	Request a free Carer's Assessment, and sign up to the Kent and Medway Carers' Emergency Card.	kent.gov.uk (search "carer's assessment")
Care Anchor	Health and wellbeing support for carers living and working around Folkestone, Hythe and New Romney.	Listed on the Folkestone and Hythe District Council website

Service	What they offer	How to get in touch
Carers First (Medway)	Support for unpaid carers living in Medway, including Carer's Assessments and peer support.	carersfirst.org.uk/medway

Mental health and wellbeing (not an emergency)

Service	What they offer	How to get in touch
NHS Kent and Medway Talking Therapies	Free, confidential talking therapies (online and in person) for people aged 17.5 and over, registered with a GP in Kent or Medway, and not already using another mental health service. Tip: you can ask for reasonable adjustments, such as written information, extra time, or clearer and more concrete questions.	Self-refer: 0333 091 0414 or online via the Kent and Medway Talking Therapies website or ask your GP
South Kent Mind	Local mental health charity offering advice, information, counselling and community activities.	Phone: 01303 250090 Monday to Friday, 9am to 4.30pm
Release the Pressure	Free, confidential support from trained staff, 24 hours a day, for anyone feeling stressed, overwhelmed or struggling.	Phone: 0800 107 0160 Text: KENT (or MEDWAY) to 85258

LGBTQ+ affirming support

Service	What they offer	How to get in touch
Switchboard LGBTQ+ Helpline	A national listening service run by LGBTQ+ volunteers, for anyone who wants to talk about anything, including grief and family.	Phone: 0800 0119 100 Website: switchboard.lgbt

Part 6: If things become too much

Getting help quickly

- **If someone is in immediate danger or needs urgent medical help:** call 999 or go to A&E.
- **Urgent mental health support, any time:** call NHS 111 and choose the mental health option.
- **Samaritans, any time:** call 116 123 (free).
- **Prefer to text?** Text KENT (or MEDWAY) to 85258.
- **Folkestone Safe Haven:** a calm, drop-in space for adults (18+) who are struggling or heading towards crisis. No referral or appointment needed. Open 6pm to 11pm every day at 3 Rendezvous Street, Folkestone, CT20 1EY.
- **Other Safe Havens:** Ashford (William Harvey Hospital, 6.30pm to 11.30pm daily), and Medway and Thanet (both open 24 hours). Full list at kmhealthandcare.uk (search "Safe Havens").

Safe Havens are not suitable for urgent medical care, for example after self-harm. In that case, go to A&E or call 999.

Telling services you are Autistic. It can help to say that you (or your family member) are Autistic and what helps communication, such as needing written information, a quiet room, or more time. You have a right to reasonable adjustments.

Part 7: Words explained

Word	What it means
Anticipatory grief	Grief that starts before someone dies, while they are seriously ill.
Monotropism	A way of thinking where attention flows deeply into one or a few things at a time. Many Autistic people are monotropic.
Interoception	Noticing signals from inside your body, such as hunger, thirst, tiredness, or emotions. This can work differently for Autistic people.

Word	What it means
Masking	Supressing or changing natural Autistic responses to avoid negative responses from others. It is often tiring.
Shutdown	Going quiet and withdrawing when things are too much.
Meltdown	Becoming very distressed when overwhelmed. It is not a tantrum or a choice.
Stimming	Repeated movements or sounds (like rocking, pacing or humming) that help a person feel calm and regulated.
Reasonable adjustments	Changes services must make so that disabled people, including Autistic people, can use them fairly.
Carer's Assessment	A free conversation with the council, or a carers' organisation, about how caring affects your life and what support could help.

Service details were checked in September 2026. Services, opening times and eligibility can change, so please check with each service before relying on the information here.