
Anticipatory Grief

When you grieve before the goodbye

Grief can begin while someone is still here

Anticipatory grief describes the emotional responses that can arise when a significant loss is expected or already unfolding. It may appear after a terminal diagnosis, progressive illness, dementia, serious disability, repeated hospital admissions or a gradual loss of independence. It can also arise while waiting for test results or a prognosis, when the future suddenly feels uncertain.

This grief is complicated by the fact that the relationship is still present. You may be trying to stay connected to today while your mind repeatedly travels into a feared tomorrow. Love, hope, sadness, anger, dread, gratitude and exhaustion can all exist at the same time.

What may already be changing

The future	Plans, assumptions and shared expectations may suddenly feel uncertain.
The relationship	Roles can shift from partner, child or friend towards caregiver, advocate or decision-maker.
Independence	You may be witnessing changes in mobility, communication, memory, personality or everyday ability.
Daily life	Appointments, medication, care tasks and vigilance can begin to organise the whole week.
Your sense of safety	The knowledge that a death or major change may be coming can make ordinary life feel fragile.
Identity	You may wonder who you will be if the relationship or caring role changes.

Grieving what may happen does not mean you have stopped valuing the person who is here now.

Anticipatory grief is not a prediction of how you will feel after the eventual loss. It is its own experience, shaped by uncertainty, caregiving, changing roles and the emotional strain of living alongside what may be coming.

Hope, fear, guilt and caregiver exhaustion

People sometimes believe they must choose between hope and realism. In practice, both can coexist. You can hope for comfort, treatment, more time, a meaningful day or a change in prognosis while also preparing for possibilities you desperately wish were not real.

Guilt about grieving too early

A common thought is: 'They are still here - I shouldn't be grieving.' But you may already be experiencing genuine losses: changed communication, altered routines, reduced independence, lost plans, or the disappearance of parts of a relationship you relied upon. Recognising these changes does not diminish the person.

Caregiver exhaustion and resentment

Caring can contain love and exhaustion together. You may feel irritated by repeated questions, appointments, disturbed sleep, responsibility or the loss of privacy and freedom. Then guilt may arrive because the person is ill. Resentment does not automatically mean lack of love; it can be a signal that your own needs have been pushed beyond capacity.

Dementia and gradual change

With dementia and some neurological conditions, grief can recur as abilities, recognition, personality or communication change. Families may feel they are repeatedly adjusting to a new version of the relationship. Avoid language that erases the person while they are alive; instead acknowledge both what has changed and what remains.

Waiting for results or prognosis

Uncertainty can produce hypervigilance: checking phones, researching symptoms, rehearsing conversations and imagining every outcome. Try to distinguish what is known today from what is feared. If possible, write medical questions down and use trusted clinical sources rather than repeatedly searching when anxiety is escalating.

The pressure to make every moment meaningful

Knowing time may be limited can create another burden: the belief that every conversation must be profound and every day must become a memory. Ordinary life still matters. Watching television, sitting quietly, arguing about something small, sharing food or doing nothing special can all remain part of a real relationship.

You do not have to turn every remaining day into a perfect goodbye. You are allowed to keep living inside the relationship.

Families, conversations and preparing without giving up

People in the same family may be at very different points. One person may want detailed information and practical planning; another may avoid discussing death. One may remain strongly hopeful while another needs to prepare. These differences can become painful if they are interpreted as denial, pessimism or lack of love.

Difficult conversations

When appropriate, conversations about wishes, care preferences, practical responsibilities, finances, digital accounts, dependants, pets, funerals or important possessions can reduce uncertainty later. But timing and capacity matter. Some conversations may need support from healthcare professionals, palliative-care teams, social workers or legal advisers.

Preparing is not the same as surrendering

Practical planning can coexist with treatment and hope. It can be an act of care: reducing the number of decisions that may need to be made in crisis. Focus on what is genuinely useful now rather than trying to solve every future problem in one sitting.

Children and young people

Children often notice changes even when adults try to protect them from information. Use truthful, age-appropriate language and allow questions to return. Avoid making promises about outcomes that nobody can guarantee. Schools may be able to provide pastoral support when a close family member is seriously ill.

When the person does not want to talk

Not everyone wants explicit conversations about dying. Connection can happen through ordinary presence, practical help, touch if welcomed, music, memories, humour or simply sitting together. Respecting someone's preference does not mean you must carry your own fear alone; find another safe person or professional with whom you can speak openly.

After the anticipated death

Knowing a death may happen does not mean you have 'already done the grieving'. The reality of absence is different from imagining it. Some people feel shock despite months or years of preparation. Others initially feel relief that suffering or uncertainty has ended and then feel guilty about that relief. Both grief and relief can be present without cancelling love.

Anticipation may prepare you for some practical realities. It cannot rehearse the exact emotional reality of someone no longer being there.

Reflection: holding today while acknowledging tomorrow

Use these prompts selectively. You do not have to answer everything, and you do not need to force yourself into future-focused thinking when today already feels full.

What has already changed?

What is still here today?

Known facts versus feared possibilities

What I know today: _____

What my mind is predicting: _____

What am I carrying as a caregiver or family member?

Practical responsibility: _____

Emotional responsibility: _____

Something I need help with: _____

A conversation I may need - but not necessarily today

Who could help me have it? _____

What I would like more of while there is still time

Not a perfect memory - something ordinary or meaningful: _____

Permission

I am allowed to hope and prepare.

I am allowed to feel tired.

I am allowed to enjoy an ordinary day without feeling guilty.

I am allowed to ask for help with caring.

I am allowed to have feelings I would never choose.

I am allowed to stay in today when tomorrow feels too large.

One thing that could make this week more manageable

Support, reading and a message from me

UK support

Cruse Bereavement Support provides information about anticipatory grief as well as bereavement support after a death. **Marie Curie** provides information and support around terminal illness, dying, caring and bereavement. **Macmillan Cancer Support** can support people affected by cancer, including families and carers. **Carers UK** provides information and support for unpaid carers. For dementia, **Alzheimer's Society** offers information and support for people living with dementia and those close to them.

For individual medical questions, prognosis, symptom changes or palliative care, speak with the relevant healthcare team. A GP can also discuss your own physical and mental health if caring or anticipatory grief is becoming difficult to manage.

Books

Kathryn Mannix - *With the End in Mind*. A palliative-care doctor's exploration of dying and the conversations around it.

Julia Samuel - *Grief Works*. Explores varied experiences of loss and adaptation.

Pauline Boss - *Ambiguous Loss*. Particularly useful where a person is physically present but psychological or relational aspects are changing, including some dementia experiences.

Therapeutic approaches

Person-centred therapy can hold conflicting emotions without requiring a person to choose the 'right' one. **ACT-informed work** can help someone make room for painful uncertainty while identifying what matters in the present. **Trauma-informed support** may be useful when medical crises, frightening symptoms or repeated emergencies are dominating the nervous system. **Family or couples work** can help when different coping styles are creating conflict.

A message from me

There is a particular kind of exhaustion in loving someone while also being frightened of losing them. Your mind may travel ahead to conversations you do not want to have, practical things you do not want to arrange, and a future you do not want to imagine - while another part of you is trying to stay beside the person who is still here.

You may also have thoughts that feel difficult to admit. You might want the uncertainty to stop. You might desperately need a break from caring. You might feel relief after a good appointment and dread before the next one. You may find yourself grieving changes in the person and then feel guilty because they are still alive.

Those feelings deserve understanding, not judgement. Anticipatory grief can ask you to hold two realities at once: this person is here, and something precious may be changing or ending.

You do not have to spend every moment preparing for the future. Sometimes the most important thing is much smaller: today's conversation, today's cup of tea, today's music, today's silence, today's ordinary moment.

Preparing does not mean you have given up. Grieving does not mean you have stopped hoping. And needing support does not take anything away from the love you are giving.

Maggie

Space to Breathe Therapy

This guide is for education and emotional support and does not replace individual medical, palliative-care, legal, financial or psychological advice. Support services and contact arrangements can change; check current information directly with the relevant organisation.