



SUPPORTING ANTICIPATORY GRIEF IN DEMENTIA CARE: ETHICAL PRACTICE AND COMPASSIONATE CONVERSATIONS

APPROACHES TO COMPASSIONATE AND
ETHICAL DEMENTIA CARE SUPPORT

FOUNDATIONS OF ANTICIPATORY GRIEF AND DEMENTIA



WHY ANTICIPATORY GRIEF MATTERS FOR PEOPLE AFFECTED BY DEMENTIA

Nature of Anticipatory Grief

Anticipatory grief in dementia involves ongoing loss before death, including memory, identity, and independence changes.

Impact on Carers and Whānau

Carers experience grief from personality changes and loss of shared futures, leading to complex emotional challenges.

Invisible and Complex Grief

Anticipatory grief is often unspoken, causing feelings of guilt, relief, confusion, and isolation among those affected.

Ethical Care and Compassion

Recognizing grief with compassion fosters trust, reduces isolation, and supports dignity and relational care ethics.



DAVID KESSLER'S PERSPECTIVE: GRIEF, UNCERTAINTY, AND MEANING

Non-Linear Grief Process

Grief is complex and non-linear, with emotions fluctuating especially in dementia care as changes trigger new grief waves.

Meaning in Grief

Meaning in grief helps people continue living and connecting, even alongside pain, without removing the loss's difficulty.

Anticipatory Grief and Uncertainty

Anticipatory grief involves mourning future losses and coping with uncertainty, which can cause anxiety and helplessness.

Compassionate Presence in Care

Ethical dementia care focuses on presence, listening, and acknowledging fear rather than providing answers or predictions.



What might someone be grieving through their dementia journey?

ETHICAL PRACTICE AND COMPASSIONATE COMMUNICATION



WHY WORKING WITH GRIEF IS AN ETHICAL ISSUE

Ethical Tensions in Grief Care

Grief work in dementia care involves ethical challenges due to power imbalances and vulnerability between carers and professionals.

Balancing Honesty and Hope

Deciding when and how to communicate grief requires balancing honesty with sensitivity to avoid overwhelming individuals.

Importance of Ethical Reflection

Reflecting on fears, discomfort, and team support helps reduce emotional burden and promotes compassionate dementia care.

Staying Present with Grief

Effective grief care focuses on presence, deep listening, humility, and respecting individual experiences and emotions.



LANGUAGE, PRESENCE, AND STAYING WITH UNCERTAINTY

Power of Language in Grief

Words shape how grief is experienced, either inviting connection or shutting down conversation.

Importance of Presence

Being present means attentive listening, noticing emotional cues, and allowing silence when needed.

Sitting with Uncertainty

Accepting uncertainty fosters trust and supports carers managing the unpredictability of dementia.

Ethical Care through Language

Using respectful, authentic language facilitates ethical care grounded in shared humanity.



CASE SCENARIOS, RESOURCES, AND TAKE- HOME PRACTICE

Case Study

A wife of someone with dementia says it's not my husband anymore, I feel so lonely – how do you respond from an anticipatory grief point of view:

What is happening, what changes is the wife facing?

- a) Her role as a wife has changed.
- b) Their physical relationship may have changed.
- c) Communication changes, she feels she is not talking to the same person, because the reactions and replies are changing but also are not consistent.



A wife of someone with dementia says, "It's not my husband anymore. I feel so lonely." How do you respond?



CASE SCENARIOS, RESOURCES, AND TAKE- HOME PRACTICE

What could you say in witnessing her situation?

I would encourage responses that acknowledge the loss, validate the loneliness, and recognise the anticipatory grief that is already occurring.

Examples might be:

"That sounds incredibly painful. You're still physically together, but you're already experiencing the loss of the relationship you once had."

"I hear how lonely you feel. Many partners describe feeling as though they have lost pieces of the person they knew, even though their husband is still here."

"It sounds like you're grieving the changes dementia has brought into your relationship. That's a very real and understandable grief."

"You miss being a wife in the way you've always been a wife—the conversations, companionship, shared decisions, and emotional connection."

"You don't have to carry those feelings alone. What you're describing is something many care partners experience."



CASE SCENARIOS, RESOURCES, AND TAKE- HOME PRACTICE

From an anticipatory grief perspective

The statement *"It's not my husband anymore"* is often not about rejection of the person with dementia. It may reflect:

- Grief for the loss of shared history and future plans.
- Loss of emotional connection and support between each other.
- Loss of companionship and intimacy.
- Loss of the familiar identity of the relationship.
- The gradual experience of saying goodbye while the person is still alive.

A helpful framework is:

1. Validate

1. "This is really hard."
2. "Your feelings make sense."

2. Name the grief

1. "It sounds like you're grieving the changes in your husband and your relationship."

3. Normalise

1. "Many spouses describe this same sense of loneliness and loss."

4. Support meaning and connection

1. "What parts of your relationship do you miss most?"
2. "Are there moments when you still feel connected to him?"
3. "Who is supporting you while you go through this?"



CASE SCENARIOS, RESOURCES, AND TAKE- HOME PRACTICE

What not to do

Avoid responses such as:

- "But he's still your husband."
- "You shouldn't think like that."
- "At least he's still alive."
- "You need to stay positive."

These can unintentionally dismiss the very real grief the spouse is experiencing.

A teaching point for the group

You might say:

"When a spouse says, 'It's not my husband anymore; I feel so lonely,' they are often expressing anticipatory grief—the grief of losing the relationship before losing the person. Our role is not to correct that statement but to witness it, validate it, and walk alongside them in that loss."

That response shifts the focus from *fixing* feelings to *bearing witness* to the person's grief, which is often exactly what is needed.



**"I don't visit Nana much anymore because it's upsetting when she doesn't recognise me. I know it's not her fault, but it hurts. I miss the Nana I used to have."
What is happening, what changes is Sophie facing?**



CASE SCENARIOS, RESOURCES, AND TAKE- HOME PRACTICE

What could you say in witnessing her situation?

These examples focus on **witnessing rather than fixing**, helping staff recognise and validate Sophie's experience.

"Sophie, that sounds really painful. It's hard when someone who has always known you so well no longer recognises you in the same way."

"It sounds like you're missing the Nana you used to know and the relationship you shared with her."

"What you're describing sounds like a kind of grief. Dementia can bring losses long before a person dies."

"It makes sense that you've been avoiding visits if each visit reminds you of how much has changed."

"I can hear how important Nana is to you. Even though the relationship has changed, the love and memories you have of her are still very real."



CASE SCENARIOS, RESOURCES, AND TAKE- HOME PRACTICE

From an anticipatory grief perspective

The statement "I don't visit Nana much anymore because it's upsetting when she doesn't recognise me." is often not about rejection of the person with dementia. It may reflect:

- Grief for the loss of shared history and future plans.
- Loss of emotional connection and support between each other.
- Loss of security during their time together. Being unsure of what is going to happen next.
- Loss of the familiar identity of the relationship.
- The gradual experience of saying goodbye while the person is still alive.

A helpful framework is:

1. Validate

1. "That sounds really hard Sophie."
2. "Your feelings matter and make sense."

2. Name the grief

1. "It sounds like you're grieving the changes dementia has brought to your relationship with Nana."

3. Normalise

1. "A lot of grandchildren tell me they feel sad, confused, or even hurt when a grandparent no longer recognises them."

4. Support meaning and connection

1. "What are some of your favourite memories of Nana? Are there still moments, even small ones, when you feel connected to her?"



CASE SCENARIOS, RESOURCES, AND TAKE- HOME PRACTICE

What not to do:

- "She still knows you deep down."
- "Try not to take it personally."
- "You should visit anyway because she's your Nana."
- "You'll regret it if you don't spend more time with her."
- "Why don't you visit more often?"
- "Have you tried showing her photos?"
- "If you visit regularly, she might start remembering you again."
- "Just focus on the positive moments."

These can unintentionally dismiss the very real grief the grandchild is experiencing.

A teaching point for the group

When a young person says they are avoiding visits because it's painful, they are often expressing anticipatory grief, not a lack of love. Dementia has changed the relationship, and they are struggling with the loss of recognition, connection, and the grandparent they once knew. Our role is not to persuade, reassure, or fix. Our role is to acknowledge the loss, validate the grief, and help them find ways to remain connected that feel meaningful and manageable.

When we respond to the grief
instead of the behaviour, we
create space for connection,
understanding, and support.

Thank you
Rayleen Wright



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