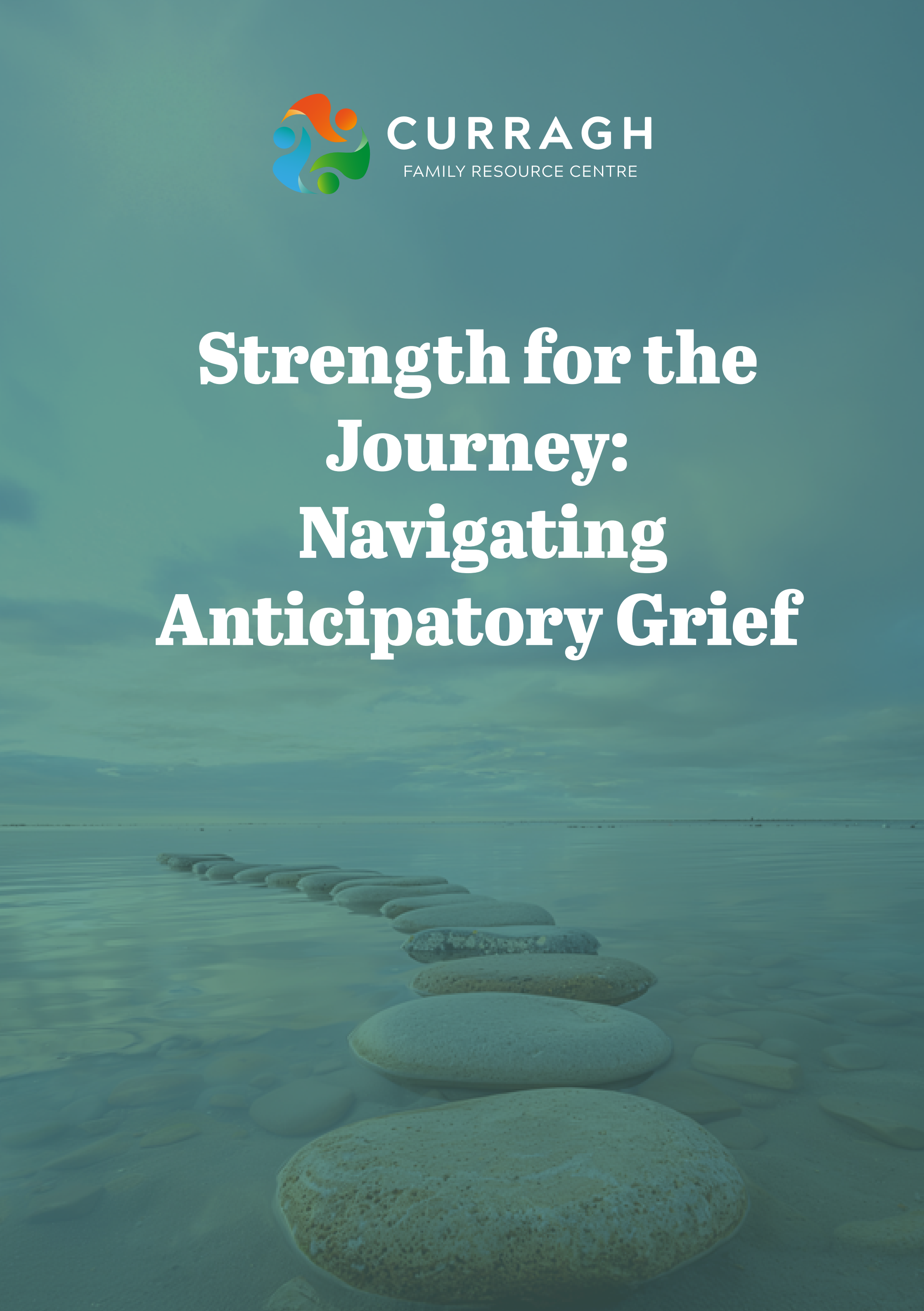
CURRAGH
FAMILY RESOURCE CENTRE

Strength for the Journey: Navigating Anticipatory Grief



This booklet is dedicated to the memory of Jason Power who died in June 2025. Jason and his family have shared their experience over a number of years, identifying gaps and challenges which inspired the creation of this booklet.

Foreword

Grief is often thought of as something that begins only after a loss, but for many, it starts much earlier, in the quiet moments of knowing a loss is coming. This is what we call anticipatory grief: the feelings of sadness, worry, anger, confusion, and even love that surface as we prepare ourselves for change and the loss of someone dear.

At the Curragh Family Resource Centre, we meet people every day who carry this feeling of grief. We see how heavy it can feel to balance the needs of today while bracing for tomorrow. We also witness the remarkable strength, compassion, and courage that emerge when people are supported to face this experience with understanding and care.

This publication was created to guide you whether you are walking this path yourself, or supporting someone who is, through the complex emotions and questions that can arise during this time. It offers reassurance that what you feel is valid, that you are not alone, and that there are ways to care for yourself and your loved ones through it all.

We hope this booklet brings you comfort, clarity, and connection as you navigate anticipatory grief.

If you are reading this booklet, you are likely connected in some way to someone who is experiencing *anticipatory grief*. You may be a family member, a person living with an incurable illness, a healthcare professional, an educator, an employer, a colleague, or a friend.

Whatever your connection, and whatever perspective you bring, we hope this booklet offers you a new way to look at and reflect on this deeply challenging time. Most importantly, we want you to know – you are not alone.

What is Anticipatory Grief?

Anticipatory grief is the emotional and psychological response to knowing that a significant death – usually the death of a loved one – is likely to happen in the near future. It begins before the actual death occurs and may involve many of the same emotions as grief after a death, such as sadness, emotional numbness, anger, fear, guilt and anxiety for example. It can often be a complex emotional space to hold.

Anticipatory grief is most commonly associated with:

- **Terminal illness** of a loved one
- **Declining health** due to dementia, Alzheimer's, or aging
- **Impending loss** of a relationship, job, or life situation

This support tool is going to focus on Terminal illness and Declining health.

Anticipatory grief begins when individuals become aware of a physical and or mental decline that will lead to the death of someone they know and care for. This can often happen after a meeting with a doctor. In a health care setting these meeting require the doctor to break bad news to the individual and their family. Conversations such as these invites the individual and the family to think about the pending death.

In cases of chronic illness, such as dementia, the decline of a loved one can be gradual and subtle, making the onset of anticipatory grief less immediate and more ambiguous. The realisation of the loss often unfolds slowly, not in a single moment, but across a series of small changes – forgotten names, lost routines, shifts in personality – that accumulate over time. This slow erosion can be emotionally disorienting, as the person is physically present but increasingly absent in other ways.

The lived experience of Anticipatory Grief

Irrespective of the path that has led you to experience Anticipatory Grief it is important to remember that it is a unique experience and can feel very different for different people, even within the same family. Each person has a different relationship with the person who is ill or dying, just as that person has different relationships with those around them.

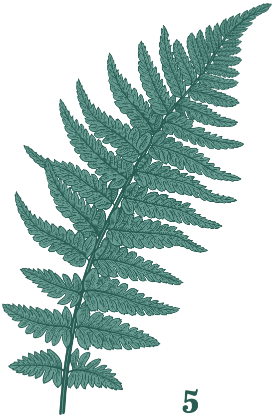
The Lived Experience of Anticipatory Grief for Those that are Dying

The lived experience of anticipatory grief for a dying person is deeply personal and complex, encompassing a range of emotional, psychological, physical, and spiritual responses as they confront their impending death. Unlike grief experienced by loved ones, anticipatory grief in the dying involves grieving their own loss – of life, identity, future, and relationships.

Anticipatory grief is not universally experienced – some may deny or avoid the topic of death until the very end. For others, support (therapeutic, spiritual, social) helps shift anticipatory grief into a process of psychological preparation and reconciliation.

Emotional Responses

- **Sadness and mourning:** Those facing death may grieve the loss of their future – dreams, milestones, time with loved ones.
- **Loneliness:** They may feel very alone in this space irrespective of how big their support system is.
- **Fear and anxiety:** Fear of the unknown, pain, or what happens after death is common. There can be anxiety about leaving loved ones behind.
- **Anger and frustration:** There may be anger over the unfairness of dying, especially if it feels untimely or unjust. The experience may also be exacerbated if there is a delay in diagnosis or if the news is not delivered in an appropriate and timely manner.
- **Guilt or regret:** They might experience regret over unresolved relationships, missed opportunities, or perceived wrongs. The guilt of "not living enough" can also feature. Wishing to die sooner than the projected course of the illness can also lead to feelings of guilt. It is not uncommon for the person who is ill to feel like they are a burden on their carers. They may also feel exhausted from the impact of their illness. Both can lead to them wishing they would die sooner which brings its own guilt.

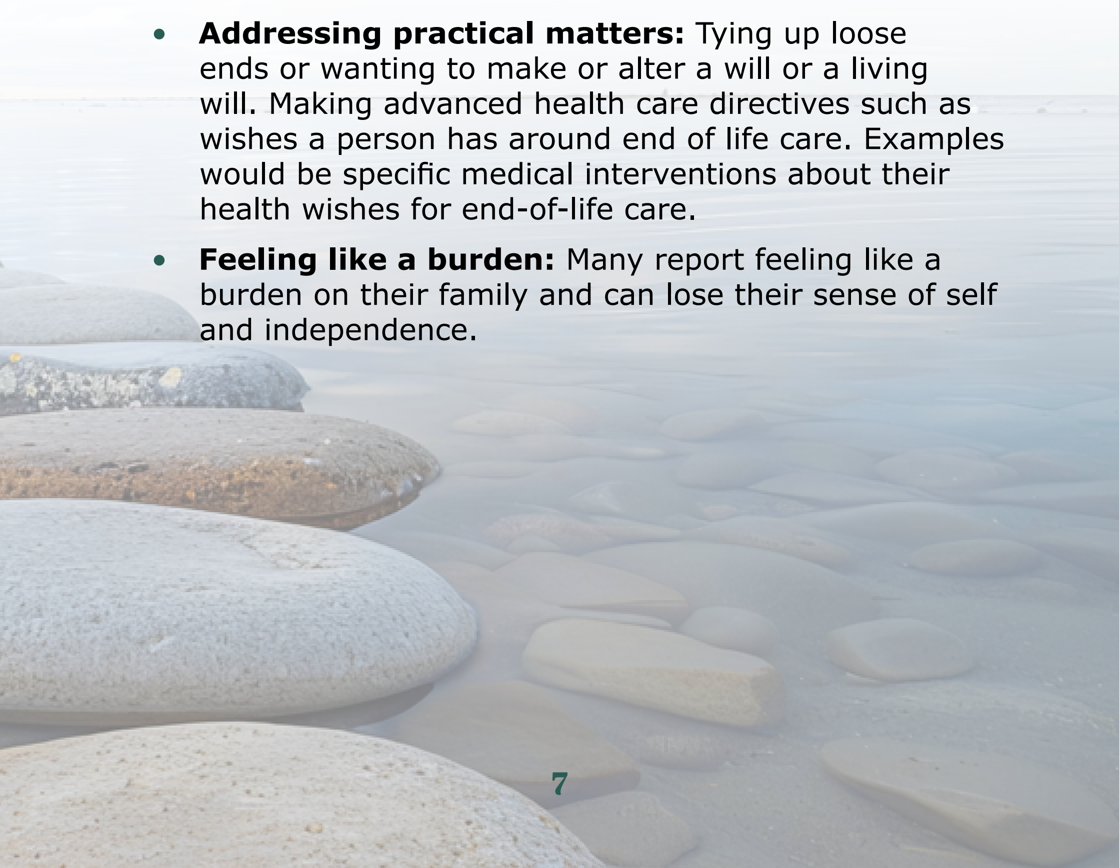


Psychological and Cognitive Changes

- **Sense of identity Loss:** Facing death often prompts a re-evaluation of self, purpose, and identity.
- **Life review:** Many engage in deep reflection, revisiting key life events and relationships, often in search of meaning or closure.
- **Disconnection or withdrawal:** As death nears, some begin to psychologically detach from the world, which can be a form of self-protection. This can be very painful for those around the individual. Their position where possible should be respected.

Relational and Social Impact

- **Rational sorrow:** The person may feel heartache over leaving loved ones behind, particularly children or dependent partners.
- **Connectiveness or lack of:** There may be a heightened need for connection, or equally, withdrawal due to emotional overwhelm or cognitive decline.
- **Role reversal:** being cared for by those they once cared for, which can impact dignity and identity.
- **Concern for loved ones:** Worry about how their death will affect family and friends, and a desire to ease their burden, is common.
- **Desire for reconciliation:** Some feel an urgency to repair or strengthen relationships before dying.
- **Addressing practical matters:** Tying up loose ends or wanting to make or alter a will or a living will. Making advanced health care directives such as wishes a person has around end of life care. Examples would be specific medical interventions about their health wishes for end-of-life care.
- **Feeling like a burden:** Many report feeling like a burden on their family and can lose their sense of self and independence.



Spiritual and Existential Aspects

- **Meaning making:** Faced with death, individuals often reflect on their lives, relationships, and accomplishments, seeking meaning or closure.
- **Peace and acceptance:** Having the support of a palliative care multidisciplinary team and/or spiritual resources can assist navigating this period greatly.
- **Meaning of life:** Others confront existential distress – a profound discomfort about the meaning (or perceived lack of meaning) of life and death. Contrary to this people also experience heightened appreciation for small moments – touch, light, memory, or music. There's often a deepening presence, where the person becomes very attuned to what is happening in the now.

Managing Uncertainty

Anticipatory Grief and Illness can often have a deep sense of uncertainty. Not having the answers to all the questions is challenging particularly for family and those living with illness, *"How will my life change? What does the future hold?"*. Uncertainty can cause anxiety. We naturally seek clarity-we are "creatures of habit" and can find change hard to adapt to. Feelings of powerlessness are common because so many aspects of illness are beyond our control. The many emotions coming to the fore as a result of this uncertainty can lead to frustration and conflict within relationships and families. Learning to live with uncertainty can be hard but developing strategies to manage it can be extremely helpful.

Focus on What You Can Control

Although illness often feels unpredictable, there are aspects that remain within one’s control. Establishing daily routines, setting small goals, and focusing on self-care practices such as eating well, physical activity within ability, and rest can create a sense of stability.

Ask Questions and Seek Information

While not every question can be answered, asking healthcare providers about treatment options, potential scenarios, and supportive resources can reduce fear. Writing down questions before appointments can also help ensure that concerns are addressed. In addition, exploring with family members or health care providers what a good death might look like, is not uncommon and can be rewarding.

Stay Present

Uncertainty often pushes people to imagine worst-case scenarios. Mindfulness, relaxation techniques, and simple practices such as deep breathing can help ground attention in the present moment, easing the burden of “what if” thinking.

Communicate Openly

Sharing worries and hopes with loved ones fosters connection and mutual support. For families with children, adjusting explanations to the child’s age and developmental level can reduce confusion and fear. Honesty, balanced with reassurance, helps children build trust and resilience. (Please see section on The Lived Experience of Anticipatory Grief for Children for more detail).

Build a Support Network

Support groups, counselling, and community resources can provide comfort and validation. Hearing from others who live with similar uncertainty may normalise the experience and lessen feelings of isolation.

Balance Hope and Realism

It is possible to hold hope for positive outcomes while also acknowledging the reality of the illness. Hope can shift over time from cure to symptom relief, to meaningful moments shared with loved ones.

When to Seek Professional Help

Sometimes uncertainty becomes overwhelming, leading to persistent anxiety, depression, or difficulty functioning day to day. In these cases, speaking with a counsellor, social worker and/or psychologist etc., can not only provide emotional support but can also give the opportunity to explore strategies for coping.

Moving Forward

Uncertainty is an inevitable part of living with illness, but it does not have to consume life. By focusing on what can be controlled, strengthening connections, and allowing space for both hope and honesty, individuals and families can find ways to live meaningfully, even in the face of the unknown.

The Lived Experience of Anticipatory Grief for those Close to the Dying Person

The lived experience of anticipatory grief for those close to the dying person is a profound and multifaceted emotional journey. It begins before the actual death, often as soon as a terminal diagnosis is given, or signs of cognitive decline appear. This type of grief encompasses not only mourning what is to come but also adjusting to the changes already happening in the relationship and in oneself.

Below is a look at what those experiences often involves:

Emotional Turmoil and Disorientation

- **Sadness and helplessness:** Loved ones grieve the gradual loss of the person as they were – physically, mentally, emotionally.
- **Fear of the future:** There's anxiety about what life will look like after the death and how they'll cope.
- **Anger or resentment:** These emotions may arise from witnessing suffering, taking on caregiving roles, anger towards healthcare services, or simply the unfairness of the situation.
- **Guilt:** Carers may feel guilty for moments of impatience, for thinking about life after the person dies, or for wanting relief from the emotional burden. Wishing the person to die to end the suffering may also occur.

Shifting Roles and Responsibilities

Role transition: Anticipatory grief often includes a role transition – becoming a caregiver, advocate, head of household or decision-maker. This shift can be empowering or deeply stressful, and it can strain relationships. The shift between partner to carer can be particularly challenging. Loved ones may grieve the loss of support in the relationship – ***"I'm giving more than I'm getting now"***.

Relational Grief and Closeness

Yearning for connection: There can be a longing for deep connections with the dying individual but also a deep sadness at the ways the relationship is changing due to the illness. Conversations may become more meaningful, or harder, depending on openness about death. The position of the dying individual, where possible should always be respected. Watching the slow decline of someone you love can be heart-breaking, particularly where cognitive decline is present: ***"I miss them even though they're still alive"***. The sense of powerlessness that arises from being unable to prevent a loved one's deterioration can leave a lasting emotional imprint.

Moments of Intimacy, Meaning, and Anticipated Regret

- **Moments of closeness and distance:** Many report moments of clarity, emotional closeness, forgiveness, or reconciliation. While others may experience emotional numbness or denial as a way to cope.
- **Striving for perfection:** There's often a sense of ***"trying to get everything right"***, saying goodbye, fulfilling wishes, being present but also fuelled by the fear of future regret.
- **Sexual connectiveness:** Sexual intimacy can be severely impacted as a result of an illness. Couples can go from a healthy and active sex life to a non-existing one. Talking about this to each other is the first step to creating a different sexual connectiveness during this anticipatory time. Simply holding each other's hands can be a great start.

Loss of Normality and Isolation

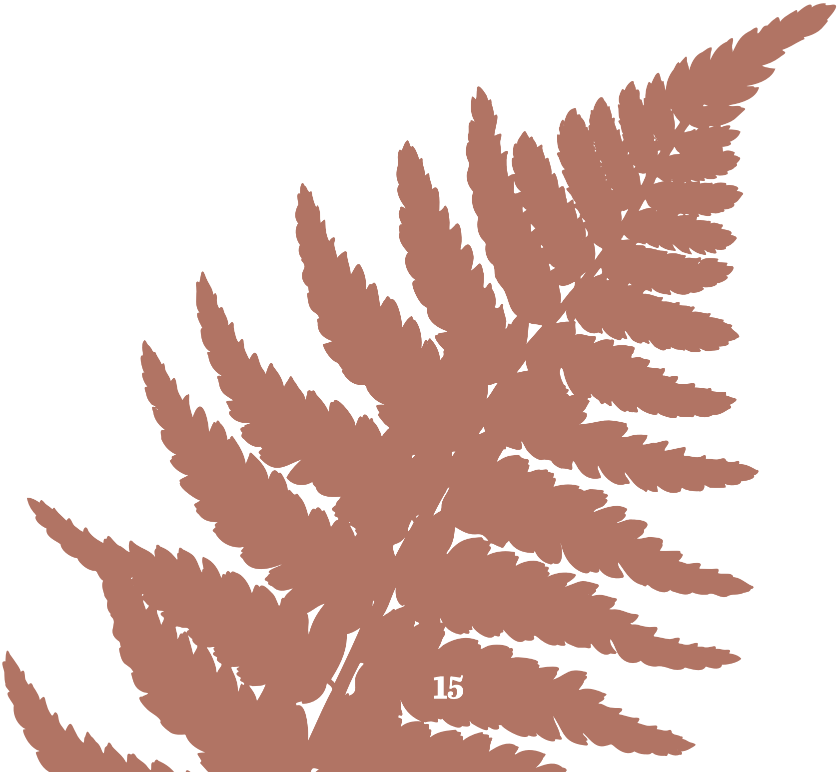
Social withdrawal and personal neglect. Life often becomes centred around the dying person's needs to the neglect of the carers needs. This can result in carers reduced connection with friends or extended family which can increase feelings of loneliness and isolation.

Parallel Grieving Processes

Grieving though still alive. Loved ones may start grieving who the person was before the illness took hold. They may also grieve the loss of shared dreams and plans for the future. Anticipatory grief can feel confusing: ***"Am I allowed to feel this way when they are still alive?"***

Clinical and Psychological Insights

Allowed time to prepare: Anticipatory grief, while painful, can allow for emotional preparation, closure, and healing of the relationship with the dying individual. However, complicated or disenfranchised grief (see explanation below) may arise if there is unresolved trauma, conflict, or lack of support. An example of a healthy bereavement outcome (Continuing Bonds) is documented below.



Complicated grief explained

Complicated grief can be known as ***Prolonged Grief Disorder***. It happens when the natural grieving process is disrupted, prolonged, or intensified, making it hard for the individual to move forward with life. It can feel like being "stuck" in grief. Complicated grief only happens to a very small number of people.

Characteristics include:

- Persistent intense sorrow or emotional pain long after the loss (typically 6+ months)
- Difficulty accepting the death
- Ongoing yearning or longing for the deceased
- Trouble re-engaging with life, goals, or relationships
- Feelings of emptiness, hopelessness, or meaninglessness

Causes can include:

- Sudden or traumatic death
- History of mental health issues
- Lack of social support
- A highly dependent or conflictual relationship with the deceased.

Disenfranchised Grief explained

This refers to grief that is not recognised, validated, or supported by society. It can lead to isolation, shame, or the inability to grieve openly.

Examples include:

- Death of an ex-spouse, stepchild, or secret partner
- Loss due to suicide, overdose, or abortion
- Grieving in stigmatised roles (e.g., a same-sex partner not acknowledged by family)
- Pet loss (which is often trivialised)
- Non-death losses (e.g., dementia, infertility, estrangement).

Why it's hard:

Because there's often no social script or ritual for mourning disenfranchised grief, those experiencing it may feel silenced, judged, or invisible in their pain.

Key Difference:

- **Complicated grief** is about the intensity and duration of grief that impairs functioning.
- **Disenfranchised grief** is about the lack of social recognition or support for the grieving process.

They can overlap: For example, if someone's grief is invalidated or hidden (disenfranchised), it may evolve into complicated grief due to lack of support.

Continuing Bonds Explained

Continuing bonds presents the idea that in death, you do not let go of someone who has died but maintain a relationship with them in death. Maintaining a meaningful connection with a loved one in death is a healthy and adaptive way of coping with the death of a loved one. This connection can take emotional, practical and symbolic forms.

Examples of continuing bonds include:

- Talking to a loved one, this maybe in thought or out loud (depending on the circumstances) or in prayer.
- Smelling a scent that reminds you of them is another example of continuing bonds.
- Keeping photos and belongings.
- Going to places that connect you with the deceased.
- Honouring traditions or rituals they valued.
- Feeling guided by their values or imagining what advice they would give in their absence.
- Incorporating their memory into important life events (e.g., weddings, birthdays).

The idea of continuing bonds contrasts with older models of grief which emphasise that the relationship ends with death and that a detachment has to occur in order for closure. Research shows that maintaining bonds with loved one in death, can be a comfort to the bereft and can assist in the grieving process. Important to note that grief is an individual and unique experience.

The Lived Experience of Anticipatory Grief for Children

"A child can live though anything, so long as he or she is told the truth and is allowed to share with loved ones the natural feelings people have when they are suffering"

(LeShan 1976)

The lived experience of anticipatory grief in children is deeply emotional and often misunderstood. Unlike adults, children may lack the language, cognitive development, or emotional tools to fully grasp or express the grief they feel as they anticipate the loss of a loved one – most commonly a parent, grandparent, or sibling. Instead, their grief may manifest through behaviour changes, body language, and shifting moods.

Parents and caregivers often struggle to communicate with their child about what is happening, for a variety of reasons. Before we explore what anticipatory grief may look like in a child, it is important to consider the value of keeping them informed during this time.

In an effort to protect their children, parents and caregivers may choose to withhold information about an incurable illness. However, terminal illness affects the entire family – children included. Children are highly perceptive and sensitive to stress and tension; they often sense when something is wrong. In an attempt to shield children, parents or carers may choose not to disclose a terminal diagnosis. However, avoiding the topic may do more harm than good. Silence can lead children to imagine scenarios far worse than reality. It may also imply that the illness is too terrible to talk about, potentially fostering an exaggerated fear of illness later in life.

Eventually, children tend to learn the truth, often through cousins, schoolmates, or family friends. Maintaining secrecy can be emotionally exhausting for caregivers and can leave children feeling excluded or unimportant. When children are not told about a diagnosis, they may experience isolation and feel as though their role in the family has been diminished.

The Benefits of Talking to Children

There are many benefits to being open with children about a diagnosis. When children are informed, they are more likely to approach their main caregiver or other trusted family members with questions or concerns. This openness removes the pressure from adults to constantly monitor their words around the child, which can be mentally and emotionally exhausting. That energy is better spent on supporting the child and managing the situation with honesty and care.

Adults often underestimate a child's capacity to handle the truth. In many cases, this hesitation reflects the adult's own difficulty in coming to terms with the diagnosis. However, uncertainty and secrecy can increase anxiety for children, and this anxiety can spill into other areas of their lives – especially school.

It's also important to inform the school, sports clubs, or other significant groups in the child's life around the same time the child is told. This helps ensure that trusted adults outside the home can keep an eye on the child and provide additional support when needed.

We cannot prevent children from feeling sadness, it is a natural and healthy part of life and a reflection of close relationships. But we can help them navigate those feelings and model the value of open communication. This not only supports their emotional well-being in the present but also lays the foundation for resilient, emotionally aware adults in the future.

Children, like everyone impacted by such news, may express a wide range of emotional responses. Below are some of the common reactions and what they might look like in children.

Confusion and Uncertainty

- Children may struggle to grasp the permanence or timeline of illness and death.
- They might ask the same questions repeatedly: ***"Are they going to get better?"*** or ***"When will they die?"***
- This uncertainty creates an underlying anxiety – they may sense something is wrong long before anyone tells them.

Emotional Shifts and Outbursts

- Feelings of sadness, fear, anger, guilt, or even relief may show up unpredictably.
- Children might act out, withdraw, become clingy, or regress (e.g., bedwetting, thumb-sucking).
- Their emotional world often reflects a mix of grief, insecurity, and a need for stability.

Imaginative Thinking and Misconceptions

- Young children may believe that their thoughts or actions caused the illness or impending death, due to magical thinking common in early development.
- Without clear, honest explanations, they may fill in the blanks with frightening fantasies or misinformation.

Shifting Roles and Responsibilities

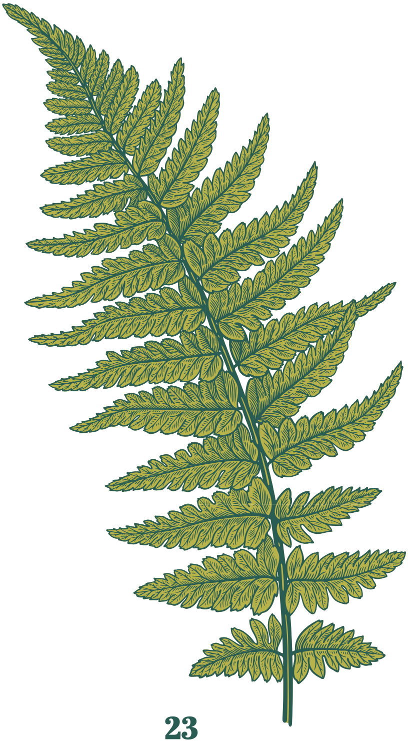
- In families where a parent is dying, children may take on caregiving roles or feel pressure to be "the strong one."
- This can create a burden that accelerates emotional maturity while also suppressing their own grieving process.

Moments of Presence and Deep Connection

- Children can have profound moments of connection with the dying person, such as cuddling, drawing together, or simply being nearby.
- These moments can become cherished memories – but also painful anticipations of what will be lost.

Silence and Isolation

- Adults may shield children from the truth, thinking they're too young to understand.
- This can result in disenfranchised grief (see explanation above), where the child's emotions are unacknowledged or minimised.
- Children may feel left out of conversations and rituals, leading to a sense of invisibility.



Supporting Children Through Anticipatory Grief:

- Use age-appropriate honesty: *"Dad is very sick; the doctors are doing everything to help him, but they don't think he will get better." "Granny has a disease called x (explain it) the doctors cannot make it go away, so we are focusing on making the most of everyday"*.
- Encourage expression through their language art, play, or stories.
- Stick to the routine to provide a sense of safety, do not spoil or reward by breaking the routine. Children do best with consistency during crisis periods.
- Let them be part of the process if they want to be. If the person who is dying is in a place of care make sure to prepare the children for what to expect, the environment and physical decline if applicable. Regarding tasks, allow them to become part of the care plan: *"I want to tidy the living room to help Mom"*.
- Irrespective of timeframes, planning and creating hope is very important. Planning movie nights, picnics in the garden/bedroom to holidays are necessary for everyone, children included. Hope can be modified throughout the anticipatory time, but there is always hope: *"We hope that Mom will have a pain free night tonight"*.
- Consider accessing therapeutic support or peer support groups designed for children if you feel that your child would benefit from it. See the end of this support tool for some resources or speak to your treating team, specifically a social worker where possible.

Children learn to manage this time by learning from the adults around them. Open communication is key. Children grieve, even if they don't show it the way adults expect. Their anticipatory grief is real and needs space to be seen, supported, and honoured.

How to Talk to Children

When asked, most children say they would prefer to hear difficult news – such as a serious diagnosis – from their parents rather than anyone else. These conversations are never easy, but being prepared can help them go as smoothly as possible.

Prepare in Advance

Take time to understand the facts before speaking to your child. If you don't have all the answers, it's okay to be honest about that. What matters most is providing age-appropriate information in a calm, clear way. Children absorb information differently than adults, so be prepared to revisit the conversation many times over the coming days, weeks, and even years.

It's important to keep having ongoing conversations as a child absorbs and processes information. Younger children, in particular, tend to think in the moment and focus on the present. If a loved one is expected to live for many months or even longer, it may be too soon to tell them directly that the person is going to die. In those situations, it can be more helpful to explain that the loved one is very sick and cannot be cured, and to give more details as the time draws closer. For example, you might say:

"Granddad has a very serious illness that doctors cannot cure. One day it will cause him to die, but that may be many months or even years from now – the doctors aren't sure. So, we are going to make the most of our time with him and hope for many more Christmases together."

Choose the Right Time and Setting

Timing and environment matter. Choose a moment when your child is most relaxed – perhaps after school, before bedtime, or during a quiet weekend moment. Many parents find that talking in the car or while going for a walk can help, as the lack of direct eye contact may make children feel less pressured or overwhelmed.

Create a Gentle and Supportive Tone

Speak slowly and gently. Let the conversation move at a pace your child can manage. It's okay to cry – this shows your child that expressing emotions is healthy and that being upset is a normal response to difficult news. Your tears can actually give them permission to show their own feelings.

Adapt the Conversation to Each Child

If you have more than one child, consider speaking with them individually. Their age, maturity, and personalities will shape how they understand and respond to the information. Some children may ask lots of questions; others may not say much at first. The goal is to create a space where they know they can return with questions at any time.

Start With What They Already Know

Begin by asking your child what they already know about the situation "What is your understanding of mom's illness? What have you heard your mom or I talk about?" This helps you understand any misconceptions they may have. If they mention the illness, ask them what that word means to them and where they heard it – whether from school, social media, or friends.

Avoid using euphemisms. While words like "tumour" or "lump" or "sore head" may seem gentler, they can be confusing. Use clear, accurate terms like "cancer," "motor neuron disease," "organ failure," or "dementia" and explain to them what they mean in age-appropriate ways.

What to Say

Explain:

- How the person's health will be affected over time.
- What the treatment plan involves, using simple and clear language.
- That the illness might affect how the person feels, acts, or thinks.
- That their routine will mostly stay the same, offering stability and reassurance.
- That the illness is not contagious – they cannot "catch" it.
- That it is nobody's fault.
- How they might be involved, such as helping in small ways or spending quality time.
- Most importantly, remind them of the love and support you all have for one another.

Involve Others in Supporting Your Child

Be sure to inform the school and other key people in your child's life – teachers, sports coaches, youth group leaders, etc. The more people who are aware and able to offer support, the better it is for both your child and your family.

Most of all

Remember you are the expert in how to comfort and reassure your child. You know best how to love them, listen to them, whether they're using words or not, include them in ways you know they're able for and would like, and support them in the ways you know work.

LOVE your child.

INCLUDE your child.

LISTEN to your child.

SUPPORT your child.

Talking to Children About Death and Dying

"...one of the good things about those illnesses that enables us to predict when a person will die is that they give the family of the dying person time to prepare themselves for the event... one of the bad things is that the family often fail to take this opportunity..."

(Parkes, 1996)

Some illnesses, such as certain cancers, are sadly incurable. One of the most difficult tasks any parent or caregiver may face is telling a child that a loved one will not recover. While there is no easy way to deliver this news, taking time to process it personally beforehand can help in preparing for an honest and compassionate conversation with the child.

As with other discussions about illness, honesty and age-appropriate language are essential. For some children, this may be their first encounter with the concept of death; for others, it may build on past experiences such as the loss of a pet or relative. Regardless of prior exposure, the news is likely to be difficult to hear. Children's responses are heavily influenced by the emotional tone set by the adults around them, and their reactions may vary – some may appear more stunned than visibly upset at first, with emotions surfacing later.

Use Clear and Direct Language

Professionals and caregivers should be encouraged to use clear terms such as "**death**," "**dying**," and "**dead**" when speaking with children. Avoiding euphemisms like "there is nothing more that can be done" they will pass as a result of the "lump" may only cause confusion. It is important to explain that all treatments that could have helped have been tried and are no longer effective while also fostering hope by reassuring them as sad as this is, they will be ok.

Caregivers should also describe the changes that may be seen in the person's health, such as increased tiredness, physical weakness, or changes in personality or memory. Where there are no visible symptoms, explaining the results of medical tests or scans can help a child understand that the illness is progressing despite the efforts of the medical team.

Introducing Palliative Care

Children should be told that, while the illness cannot be cured, there are still ways to manage symptoms like pain, nausea, and discomfort. Introducing the concept of palliative care – as a form of treatment focused on comfort and quality of life – can help children understand that while their loved one won't "get better," they can still be supported to feel as well as possible.

Creating Emotional Safety

It's important to provide children with a safe and non-judgemental space to ask questions and express feelings. Children may raise concerns or ideas that seem unusual to adults, but their perspectives are valid and should be heard with care. Answering questions honestly – even if the answer is “I don’t know” – can help build trust and foster emotional resilience.

Caregivers should reassure children that all emotions are acceptable. It’s normal to feel sadness, anger, fear, and even moments of happiness or relief. Encouraging emotional expression through play, art, writing, music, sports, or conversations with trusted adults can be particularly helpful.

Planning and Creating Memories

Where appropriate, families may wish to set shared goals or plan meaningful activities together. Whether it’s a day out, a special dinner, or simply time spent together at home, these moments can provide comfort and lasting memories for the child and the loved one who is ill.

Ongoing Support and Reassurance

It is important to check in regularly with the child to assess their understanding and offer ongoing support. Asking the child to repeat back what they’ve understood can help clarify any misconceptions. Children should be reminded frequently that no question is off limits and that support is available whenever they need it.

Supporting a child through the anticipatory loss of a loved one is a challenging but profoundly important task. When caregivers respond with openness, compassion, and clarity, they provide the child with a safe emotional foundation and lifelong tools for coping with grief and loss.

What Children Really Want to Know – by Age Group

(Adapted from The Max and Beatrice Wolfe Centre for Children, Toronto, Canada)

Children facing the illness or loss of a loved one often have fundamental questions. Providing honest, age-appropriate answers can reduce fear and build trust:

Ages 3–7: Young Children

At this stage, children think in concrete terms. Their understanding of death may be limited, and they often repeat questions to help process the concept.

Common Questions:

- “Is it my fault?”
- “Did they catch something?”
- “Will I catch it too?”
- “Who will take care of me?”
- “Where did they go?”
- “Can they come back?”

How Grief May Feel:

- Confused and unsure about what’s happening
- Scared or anxious when routines change
- Guilty if they were recently angry with the person who is ill
- Feelings may be expressed through behaviour (clinginess, tantrums, regressive behaviour like bedwetting).

Support Tips:

- Use clear, simple words (e.g., “died” instead of “went to sleep”)
- Offer reassurance about safety and routine
- Encourage emotional expression through drawing, play, and storytelling.

Ages 8–12: Middle Childhood

Children at this stage begin to understand that death is final and affects everyone eventually. They may seek explanations and can experience strong emotions privately.

Common Questions:

- “What exactly is happening to their body?”
- “Will I be okay?”
- “Can this happen to someone else I love?”
- “Why did this happen?”
- “What will change in my life?”

How Grief May Feel:

- Sense of helplessness or trying to “fix” things
- Feelings of responsibility (“Did I do something wrong?”)
- Fear that others may die too
- Changes in concentration, sleep, or appetite
- Feeling different from peers or isolated at school.

Support Tips:

- Provide honest, factual explanations appropriate to their level
- Normalise emotions – especially guilt, sadness, or anger
- Maintain routines while being flexible and responsive
- Include them in memory-making or planning when appropriate.

Ages 13–18: Teenagers

Teens have a more adult-like understanding of death but may struggle with emotional regulation. They often seek autonomy while also needing connection.

Common Questions:

- "How do I cope with this?"
- "Why does life feel so unfair?"
- "What happens after death?"
- "Will things ever go back to normal?"
- "Who can I talk to that really understands?"

How Grief May Feel:

- Emotional chaos – swings between numbness, anger, sadness
- Disconnection – from friends, family, or themselves
- Vulnerability – concerns about future security
- Isolation – feeling alone or misunderstood
- Concealing – May mask pain through withdrawal, risk-taking, or high achievement

Support Tips:

- Respect their need for space while checking in consistently
- Acknowledge that grief is messy and unpredictable
- Encourage expression through journaling, music, physical activity, or peer support
- Be open to hard questions – even if the answer is "I don't know".

The Long Term: Life Without a Parent

One of the most profound sources of stress for a parent facing a terminal illness is the question: How will my child cope when I'm gone? While the thought is heart-wrenching, it is essential to recognise that children are remarkably resilient. With the right support, they can grow into emotionally healthy, well-adjusted adults, while still carrying a meaningful connection to the parent who has died.

For families navigating an anticipated loss, there is a unique – though painful – opportunity to prepare the child in ways that sudden death does not allow. These conversations and actions, though difficult, can lay a foundation for continued emotional security and attachment long after the parent is gone.

Key elements to focus on include:

- Reassuring the child that they will continue to be loved and cared for.
- Creating memory-making opportunities (e.g., letters, videos, scrapbooks).
- Maintaining routines and predictability wherever possible.
- Appointing trusted caregivers and ensuring the child knows who will be there for them.

By intentionally involving the child in age-appropriate ways and fostering open communication, families can provide a sense of continuity, love, and connection that lasts far beyond the immediate loss.

Finding the "Right Time" for Death in the Journey of Anticipatory Grief

When facing the approaching loss of a loved one, families often wonder if there is a "right" or "best" time for death to happen. While it's natural to hope for a moment that feels peaceful or meaningful, the truth is that there is no perfect timing – only moments of connection and love that can be made along the way.

The time before a death can be a precious gift – a chance to say important things, share memories, and hold each other close. This period allows families to prepare their hearts, begin to say goodbye, and find comfort in one another. When the death happens during this space of awareness and connection, it can bring a sense of peace, even amid sorrow.

But this time can also feel too short or stretch on too long. If a loved one dies suddenly, it can leave family members shocked and unready to say goodbye. On the other hand, when the illness lingers, it can bring exhaustion and deep sadness, making it hard to hold onto hope and strength.

Ultimately, the "right time" is less about the clock and more about the moments shared – the love expressed, the forgiveness given, the quiet understanding found. Families may experience a mixture of emotions – regret, relief, sorrow, and gratitude – all at once, and that's okay.

The most important thing to remember is that the journey through anticipatory grief is about being present with your loved one and with each other, cherishing the time you have together, no matter how much or how little that may be.

Supporting a Child at School When a Family Member is Terminally Ill

When a child has a parent, grandparent, or close family member who is terminally ill, school can become a challenging place full of mixed emotions and new stresses. With the right support, children can feel safe, understood, and cared for both at home and at school.

Why School Support Matters

- A child's world extends beyond home. School is where they spend much of their time, learn, socialise, and find routine.
- School can provide stability and normalcy. Familiar teachers, friends, and activities can offer comfort when home life feels uncertain.
- Teachers and staff can watch for signs of distress. Early support can prevent emotional or academic struggles from worsening.
- Peers can be a source of friendship or, unfortunately, misunderstanding. Awareness helps foster kindness and inclusion.

How Families Can Help Prepare the School

- Inform key people early. Share information about the illness and anticipated changes with the child's teacher, principal, school counsellor, and any other relevant staff. It might be best to arrange a meeting with all relevant parties to create clean lines of communication.
- Discuss how much the child wants shared. Respect the child's wishes about what their peers and teachers know while ensuring the school is equipped to provide support.

- Work with the school to plan accommodations. This might include flexible attendance, extra breaks, or quiet space if the child needs time out during difficult days.
- Provide resources. Offer materials or suggest visits from counsellors who can talk with the child or classmates about illness and grief in an age-appropriate way.

Supporting the Child at School

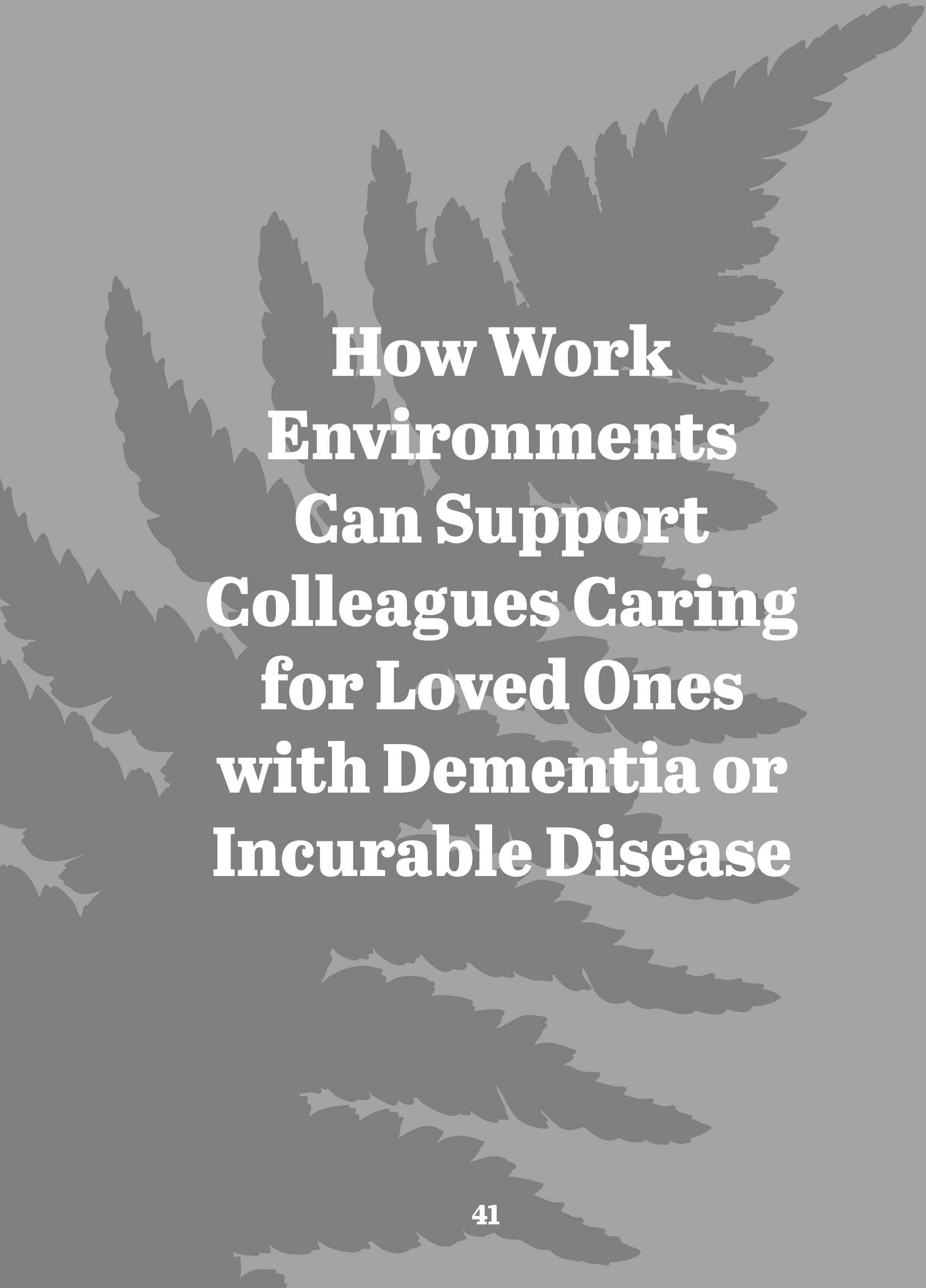
- Maintain routines where possible. Consistent schedules can provide a sense of security.
- Encourage open communication. Let the child know it’s okay to talk about their feelings with trusted adults at school.
- Be mindful of changes in behaviour or performance. Signs such as withdrawal, irritability, declining grades, or frequent absences may indicate they need more support.
- Help the child develop coping strategies. This could include journaling, art, physical activity, or simply having a trusted friend or adult to talk with.
- Prepare for special events. Holidays, birthdays, or family celebrations can be harder for children dealing with illness and grief; planning ahead helps.

Supporting the School

- Stay in regular contact with teachers and counsellors. Updates on how the child is coping at home and at school help everyone stay informed.
- Encourage the child to share their needs. Empower them to ask for help or breaks as needed.
- Advocate for professional support if needed. School psychologists, social workers, or grief counsellors can provide valuable assistance.

Remember

Every child’s experience is unique. Patience, kindness, and open hearts from family and school can make a powerful difference in helping a child navigate this difficult time with resilience and hope.



How Work Environments Can Support Colleagues Caring for Loved Ones with Dementia or Incurable Disease

When an employee is caring for a loved one with dementia or a terminal illness, the emotional and practical burden they carry is often invisible. These situations can be overwhelming, filled with uncertainty, sadness, and daily decision-making. Many individuals continue to work while navigating the complexities of caregiving – whether by choice, necessity, or both.

Workplaces have a unique opportunity to make a difference during this time. Standing out for all the right reasons is something to strive towards. A compassionate, flexible, and informed work environment can help colleagues feel supported, seen, and respected – not only as professionals, but as people. Small acts of understanding can reduce stress, prevent burnout, and foster a culture of empathy and resilience across the organisation.

The following guide outlines ways employers and teams can support colleagues during one of the most challenging periods of their lives.

Foster a Culture of Compassion and Awareness

- **Normalise caregiving conversations:** Encourage openness around caregiving responsibilities so colleagues don’t feel isolated or ashamed.
- **Offer dementia and palliative care education:** Provide optional lunch-and-learn sessions or resources to help staff understand what their colleagues may be going through. Ideally this should be done with the consent of the those directly impacted.

Encourage Flexible Work Arrangements

- **Flexible hours or shift adjustments:** Let employees adjust their schedule to attend medical appointments, provide care, or simply rest.
- **Remote or hybrid work options:** If possible, allow employees to work from home when needed, especially during emotionally or logistically intense times.

Provide Emotional and Practical Support

- **Employee Assistance Programs (EAPs):** Promote access to free counselling, grief support, or caregiving resources.
- **Peer support groups:** Facilitate internal support circles for those caring for family members or going through anticipatory grief.

Offer Compassionate Leave

- **Extended or flexible leave policies:** Consider providing compassionate leave that allows for both care and anticipatory grief needs – not just bereavement after death.

- **Unpaid leave with job security:** For those needing more time, make sure they understand their rights and options.

Communicate With Empathy

- **Have a sensitive point-of-contact:** Assign a trusted HR representative or manager who can check in privately and empathetically.
- **Respect privacy but show presence:** A simple ***"We're thinking of you – let us know what you need"*** can go a long way.

Reduce Non-Essential Pressure

- **Adjust workload temporarily:** Offer lighter responsibilities or redistribute tasks if the employee is having some difficult in navigating and juggling.
- **Avoid punitive measures** for minor lapses in performance or attendance during these periods

Recognise the Long-Term Nature of Caregiving and Grief

- **Grief doesn't start at death:** Understand that anticipatory grief can be as disruptive as grief after death – emotions may surface unpredictably.
- **Support continues after the loss:** Consider ongoing check-ins even months after the death has occurred.

Why This Matters

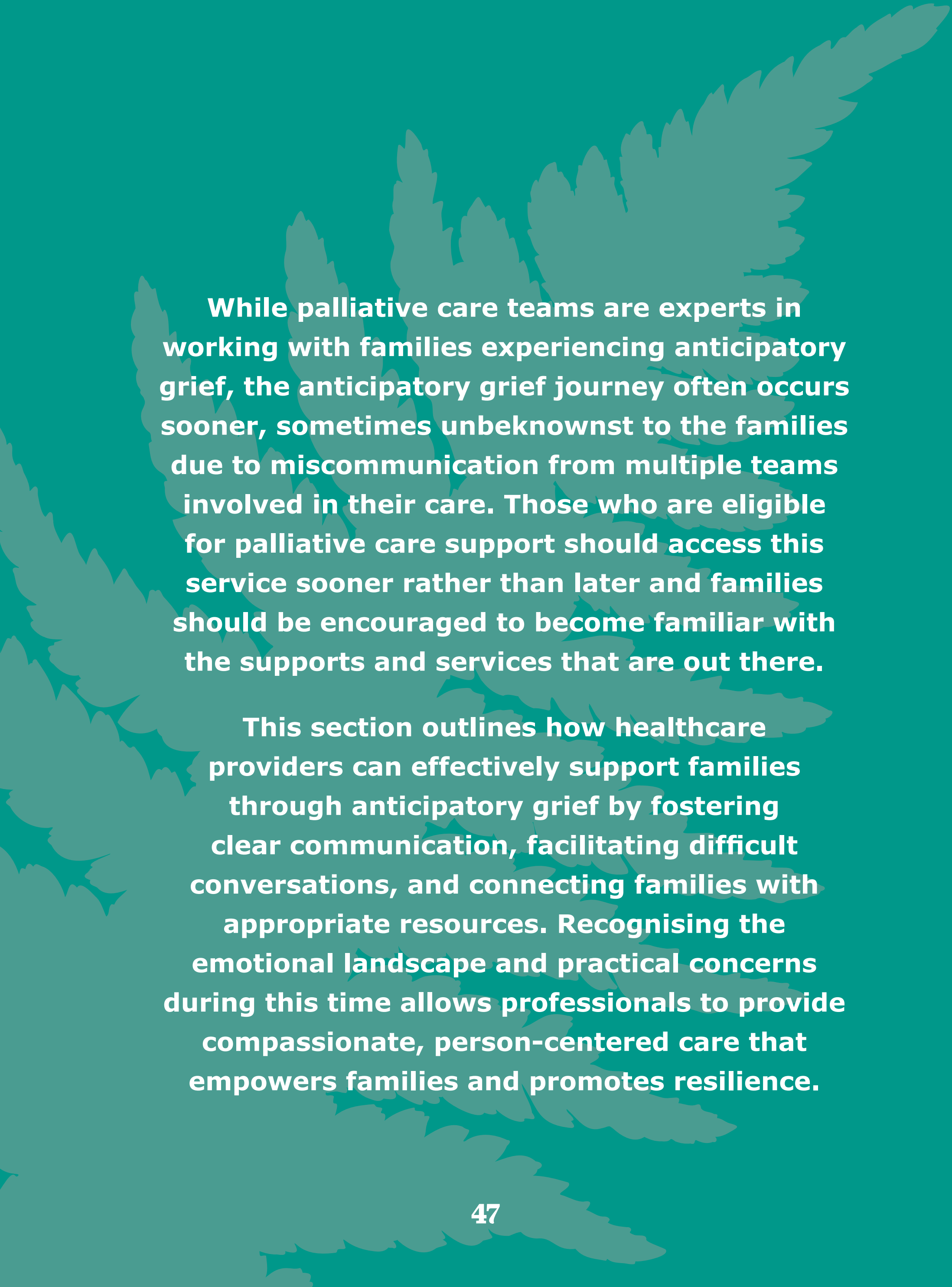
When a colleague is supporting a loved one with dementia or terminal illness, they are often balancing overwhelming emotional, physical, and logistical demands. A responsive, supportive workplace can:

- Reduce stress and burnout.
- Improve loyalty and retention.
- Create a safer and more connected team culture.

Fostering an environment where colleagues feel genuine empathy and support can be challenging but equally very rewarding. Ultimately, being flexible, kind, and informed makes a world of difference.

The Role of the Treating Medical Team During Anticipatory Grief

Anticipatory grief presents unique challenges for families facing the terminal illness or cogitative demise of a loved one. During this period, emotional, psychological, and practical needs evolve rapidly, requiring sensitive, coordinated support. As professionals involved in the care of these families, it is essential to understand the multifaceted role the medical team plays, not only in managing clinical care but in addressing the holistic needs of patients and their families. The importance of utilising the multidisciplinary team is paramount. Occupational therapists, Physiotherapists, Social Workers, Dietitians, Psycho-oncology for example all have expertise that can assist in making this time easier for the family.



While palliative care teams are experts in working with families experiencing anticipatory grief, the anticipatory grief journey often occurs sooner, sometimes unbeknownst to the families due to miscommunication from multiple teams involved in their care. Those who are eligible for palliative care support should access this service sooner rather than later and families should be encouraged to become familiar with the supports and services that are out there.

This section outlines how healthcare providers can effectively support families through anticipatory grief by fostering clear communication, facilitating difficult conversations, and connecting families with appropriate resources. Recognising the emotional landscape and practical concerns during this time allows professionals to provide compassionate, person-centered care that empowers families and promotes resilience.

Providing Clear and Compassionate Communication

- **Honesty with empathy:** The medical team should offer realistic, clear, and compassionate updates about the diagnosis, prognosis, uncertainty in the prognosis and treatment options.
- **Preparing families for change:** Helping families understand what to expect as the illness progresses allows them to emotionally prepare and make informed decisions.
- **Repeating and clarifying:** Families may not absorb everything at once. The team should be prepared to repeat information and answer questions multiple times with patience.

Supporting Emotional and Psychological Needs

- **Acknowledging grief:** By recognising the presence of anticipatory grief, the team validates the emotional experience of families.
- **Referring to psychosocial support:** Connecting families with social workers, counsellors, bereavement specialists, and chaplaincy teams helps them process their emotions and prepare for the road ahead.
- **Being emotionally present:** Sometimes, simply bearing witness to a family’s pain without trying to “fix” it is a powerful act of care.

Creating a Sense of Continuity and Trust

- **Consistency in care:** Regular and familiar interactions with the same members of the care team foster trust and reduce feelings of chaos or abandonment.
- **Building relationships:** A supportive therapeutic relationship gives families a safe space to share concerns, fears, and hopes.

Offering Practical Guidance and Future Care Planning

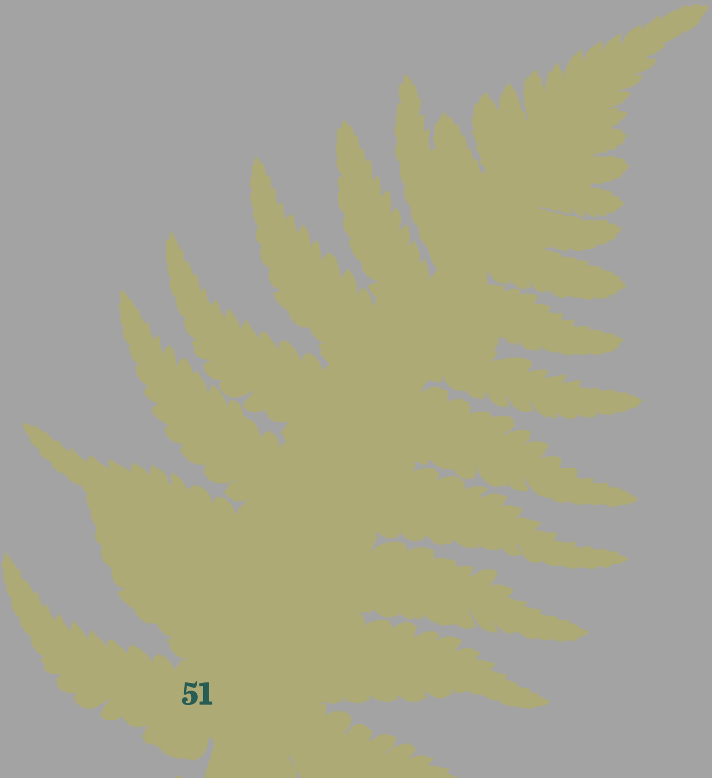
- **Explaining palliative and end-of-life care:** Educating families about the goals of palliative care – including comfort, dignity, and quality of life – is essential.
- **Explaining Advance Care Planning** and **Advance Directives**
- **Helping with decision-making:** Families often struggle with choices about treatment, care settings, or advanced directives. The medical team guides them through these decisions with clarity and compassion. Irrespective of the plan, the most important aspect of this process is the person who is dying and that their wishes are represented. A personalised care plan which is reflective of their voice and lens should be put in place.
- **Encouraging memory-making and legacy planning:** Gently encouraging families to spend meaningful time together and consider legacy activities (e.g., letters, photos, memory boxes) can provide a sense of purpose and connection.

Supporting the Patient's Role as a Parent or Loved One

- **Preserving identity:** Help patients remain engaged in their role as a parent, spouse, or loved one, even if their physical ability is declining.
- **Making space for important conversations:** Where appropriate, create opportunities or provide support for the patient to talk to children or family members about their condition.

In essence, the treating medical team becomes a steady anchor for families navigating anticipatory grief – offering not just clinical expertise, but also presence, reassurance, and care through one of life's most emotionally complex journeys. When managed poorly, it can lead to resentment and complicate the grieving process. When done well, families are afforded the opportunity to navigate this space without regret.

Resources



Creating a Memory Box

A Gift of Love for the Future

A memory box is a beautiful and lasting way to leave behind your love, memories, and guidance for your child. It offers comfort and a tangible connection that your child can turn to whenever they need to feel close to you. Each item you include – no matter how small – becomes part of your story together.

What to Include

You can tailor the box to your child's age, interests, and your unique relationship. Consider including:

- **Letters or Notes:** Write to your child about your memories together, what you love about them, and your hopes for their future.
- **Photographs:** Include photos of shared moments – holidays, daily life, or special events – with captions or short notes.
- **Meaningful Items:** A piece of jewellery, a favourite book, a keychain, a toy, or even a scarf they liked you wearing – anything with emotional significance.
- **Keepsakes:** Birth certificates, handprints, birthday cards, or special drawings.
- **Advice or Reflections:** Share your thoughts on growing up, handling challenges, love, friendship, or things you've learned in life.
- **Recordings or Videos:** A voice recording or video message can be a powerful way for your child to hear your voice and feel your presence.

Memory Box Prompts

These can help get you started when writing or selecting items:

- *"The day you were born, I felt…"*
- *"My favourite memory of us is…"*
- *"What I admire most about you is…"*
- *"When you're feeling sad, remember…"*
- *"I always laughed when you…"*
- *"A lesson I hope you carry with you is…"*
- *"What I hope for you in life is…"*

Getting Support

Creating a memory box can be emotional. If you'd like help or simply someone to talk to, reach out to your palliative care social worker or a support organisation. You're not expected to do this alone. This can be created with someone supportive in the child's life, without expectation or pressure for the person who is dying.

Even one note or memento means more than you may know – it becomes part of your child's emotional foundation and lifelong connection with you. Someone else might support this with a recording or sharing thoughts or messages as it may not be something everyone can do.

Writing for the Future

"Writing for the Future" is a special initiative by Cancer Focus Northern Ireland that helps individuals create a lasting legacy for their loved ones. This often takes the form of a written document – sometimes accompanied by photographs – compiled into a book like ***This Is Your Life***. Working alongside a medical social worker ideally, individuals facing anticipatory grief are gently guided through a series of reflective questions. Their conversations are recorded, transcribed, and thoughtfully assembled with photos, creating a deeply personal gift for children or family members to receive – either before or after their death.

While the desire to leave something meaningful is strong, starting this process can be emotionally overwhelming. That's why it's important not to do it alone. Support from a social worker or a trusted family member can make the journey more manageable and healing. This is a beautiful and enduring legacy to leave behind – but if it feels too difficult, be gentle with yourself. Not everyone will be able to complete it, and that's okay.

A sample outline of themes and guiding questions follows below.

Legacy Book – Sample Table of Contents

Chapter 1: Roots and Origins

- Where were you born, and what was your family like?
- What cultural or ethnic traditions shaped your upbringing?
- Who are your ancestors or relatives you admired, and why?

Chapter 2: Childhood and Early Life

- What are your earliest memories?
- What games did you play, and what made you feel happy or safe?
- Who influenced you most as a child?

Chapter 3: Lessons from Life

- What’s a difficult moment that taught you a valuable lesson?
- What’s something you wish you knew earlier in life?
- How did failure or disappointment shape your path?

Chapter 4: Love and Relationships

- How did you meet the people you’ve loved deeply?
- What have you learned about love, friendship, and loyalty?
- What do you want future generations to know about building strong relationships?

Chapter 5: Parenthood and Family Values

- What did being a parent (or child) teach you?
- What family traditions or values do you hope are never lost?
- What advice would you give to future parents?

Chapter 6: Work, Dreams, and Aspirations

- What were your dreams growing up? Did they change?
- What work brought you joy or meaning?
- How did you define success?

Chapter 7: Faith, Beliefs, and Meaning

- What do you believe in deeply, and how did that belief grow?
- Has your faith or philosophy changed over time?
- What gives your life meaning?

Chapter 8: Passions and Joy

- What hobbies or activities made your soul light up?
- How did you express creativity or have fun?
- What did you do just for yourself?

Chapter 9: The World as You Knew It

- What global or national events changed your life?
- What’s one big way the world has changed during your lifetime?
- What would you tell future generations about “your era”?

Chapter 10: Final Thoughts and Hopes

- What legacy do you want to leave?
- What’s one piece of advice you hope others carry with them?

Recommended Reading & Resources on Anticipatory Grief

Please note: The resources listed below are intended as a sample of what is available. They represent a starting point rather than a comprehensive list.

For Children

- Why Mum? A Small Child with a Big Problem – Catherine Thornton (Veritas, 2005)
- Gentle Willow: A Story for Children About Dying – Joyce Mills (2004)
- Always and forever – Debi Gliori & Alan Durant (2013)
- Badger's Parting Gifts – Susan Varley
- No Matter What – Debi Gliori
- The Huge Bag of Worries – Virginia Ironside (2016)
- What's Dead Mean? How to Help Children Cope with Death – Dorris Zagdanski (2010)
- Lifetimes: The Beautiful Way to Explain Death to Children – Bryan Mellonie
- The Invisible String – Patrice Karst

Children's Workbooks & Useful Websites

- When Someone Has a Very Serious Illness: Children Can Learn to Cope with Loss and Change – Marge Heegaard (Woodlands Press, 1942; still reprinted)
- Muddles, Puddles and Sunshine: Your Activity Book to Help When Someone Has Died – Diana Crossley (Winston's Wish)
- When Someone You Love Has Cancer: A Guide to Help Kids Cope – Alaric Lewis
- Talking to Children – Information and Support – Macmillan Cancer Support (www.macmillan.org.uk)
- Talking to Children When Someone Close is Ill – Marie Curie Cancer Care (www.mariecurie.org.uk)
- Winston's Wish (https://winstonswish.org/) Winston's Wish is a charity that offers free, accessible online grief support to children and young people (aged 25 or under) across the UK who are bereaved or facing the death of someone important.

For Teens & Young People

- When Your Parent Has Cancer: A Guide for Teens – National Cancer Institute (2012)
- The Secret C: Straight Talking About Cancer – Julie A. Stokes (Winston's Wish, 2000)
- Two Weeks with the Queen – Morris Gleitzman (novel for older children/teens, exploring sibling illness)

For Parents & Adults Supporting Children

- Grief in Young Children – Atle Dyregrov
- A Handbook of Children's Grief: For Adults Supporting Children – Atle Dyregrov
- It's OK That You're Not OK – Megan Devine (for adults navigating their own grief while supporting children)

Irish Supports & Programmes

- Climb® (Children's Lives Include Moments of Bravery) – for children aged 5–12 impacted by a parent's or significant other's cancer diagnosis.
  - → 6-week evening programme using drama, art, and play.
  - → Contact your hospital social worker or the Irish Cancer Society for details.
- Irish Cancer Society – information and resources on talking to children about cancer: cancer.ie
- Irish Hospice Foundation: hospicefoundation.ie

Books for Adults

1. Understanding the Grief and Loss Experiences of Carers: Research, Practitioner and Personal Perspectives

   Editors: Kerry Jones & Joanna Horne.

   Explores carers' experiences, including anticipatory grief: losses of future, freedoms, etc

2. Harnessing Grief by Maria J. Kefalas

   Memoir / self-help about living with grief when a child has a serious, life-limiting illness. The author writes about anticipatory grief as part of the journey.

3. The Grieving Brain: The Surprising Science of How We Learn from Love and Loss by Mary-Frances O'Connor

   More scientific, exploring what's happening in the brain with grief; useful for understanding what one is feeling.

4. Grief Works by Julia Samuel

   A compassionate guide through grief. While not only about anticipatory grief, many of the principles are also applicable (preparing, reflecting, coping with change). Available in Ireland.

5. Bearing the Unbearable: Love, Loss, and the Heartbreaking Path of Grief by Joanne Cacciatore & Jeffrey Rubin

   A book of essays and reflections.

6. No Time for Tears: Coping with Grief in a Busy World by Judy Heath

   Addresses how grief gets compressed/lost in busy life, which is often the case when someone is anticipating loss.

7. A Practical Guide for Grief & Loss by Diana Hutchison

   Shorter guide, more workbook/self-help style, helps with tools and strategies. Rakuten Kobo

8. Seasons of Grief: Creative Interventions to Support Bereaved People by Claudia Coenen (Useful in creative ways (writing, art, reflection) to process grief).

About the author

Yvonne O’Meara is a Systemic Psychotherapist and Psychosocial Oncologist who has been supporting patients and families in cancer care and palliative settings since 2004. She has worked in Ireland and North America and co-founded the ISGO-PPI (Irish Society of Gynaecological Oncology Public and Patient Involvement) to ensure that the voices of patients are central in research. in 2025 ISGO-PPI won the IGCS Dicey Scroggins Distinguished Advocate Award. Her areas of special interest include anticipatory grief, bereavement, and psychosexual wellbeing after cancer. Since 2020, Yvonne has coordinated Women’s Cancer Survivorship Research at UCD School of Medicine as part of the Irish Cancer Society’s Women’s Health Initiative at the Mater Hospital. Outside of work, Yvonne is married and adores watching her three daughters grow up.

CURRAGH
FAMILY RESOURCE CENTRE

Curragh Family Resource Centre

Curragh Family Resource Centre is a community-based organisation serving the Curragh and surrounding areas of Co. Kildare and is funded by TUSLA. The Centre is committed to providing accessible, high-quality support services and programmes that strengthen families, foster social inclusion, and promote community development.

Our work encompasses therapeutic support, family support, youth resilience, and targeted initiatives aimed at addressing gaps. Curragh FRC collaborates with statutory, voluntary, and community partners to deliver evidence informed interventions that enhance individual and collective wellbeing.

As part of our work and approach at the Curragh Family Resource Centre, we identify gaps in services and supports through the real-life challenges and experiences shared by the families who engage with us. Guided by our commitment to advocacy and social justice, we aim to recognise these gaps and injustices and, where possible, to advocate on behalf of those affected or to raise awareness of the issues involved.

One such issue that has been brought to our attention is anticipatory grief and the limited availability of accessible information and supports – particularly in cases where the illness does not fall under an oncology department.

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