

Grief And Loss Among Care Providers And Receivers

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Introduction

As people age, they usually experience multiple losses which make them vulnerable to grief in ways they may not even recognise. In this course, we will be talking about grief from four viewpoints:

- 1) The view of the person with a chronic illness.
- 2) The view of the person with dementia.
- 3) The view of the family carer looking after a person with a chronic illness.
- 4) The view of the family carer looking after a person with dementia.

If you are a *professional* carer, you may experience some of the same grief symptoms as the family carer, especially if you have a strong relationship with the person you are caring for. If you have some other role in a residential care community or an adult day centre, this course will help you to build stronger relationships with your residents/clients and their families by increasing your understanding of what they are experiencing.

Traditionally we think of people as grieving when someone dies, but grieving is really about loss, and people experience many losses as they age, so this course is divided into four sections:

- 1) A description of the grieving process as we understand it.
- 2) Building awareness of the range of losses people are likely to experience.
- 3) Ideas for helping people to cope, no matter where they are in the grieving process.
- 4) Ideas for a residential care community or adult day centre memorial service.



Part 1: Grieving Is A Process

Let's begin with a story...

Two men were fishing. Their luck was incredible. They caught more fish than they had ever caught before. As the sun was going down and they started to pack up, one fisherman said to the other, "You'd better mark this place."

When they got back to the dock, the first fisherman said, "Did you mark the place?"

The second fisherman said, "I did. I put an 'X' on the side of the boat just over the lucky spot."

"But," sputtered the first fisherman, "how do you know we're going to be able to rent the same boat tomorrow?"

What on earth does that joke have to do with grief and loss? Let me explain...

Firstly, one of the elements of humour is surprise. Not all jokes have a surprise ending, but some do. This one does. You would expect the fisherman who suggested his partner mark the good fishing spot to be upset that he marked the side of the boat and not the actual position in the water, but instead, his only worry is that they won't get the same boat tomorrow. Things are not always as you expect. Well, some of the things we're going to work through relating to how people express grief are likely to surprise you too, because grief is about much more than sadness. The second point this joke makes in relation to grief is that when we are grieving, we don't always think clearly or logically. Indeed, sometimes people who are in deep grief seem to have early signs of dementia.

Signs of grief

Many people associate grief with sadness and crying; with the profound sorrow generated by the death of someone we love. That comes close to the dictionary definition, but grief is much broader than that. Grief is about loss, and loss takes many forms, as we will discuss. Grief over these varied losses is expressed by sadness in many people, but it may also take the form of:

- anger
- anxiety
- irritability, being 'ready to snap'
- restlessness
- guilt
- fear
- indecision, inability to focus, mental 'slowing down'
- numbness
- hopelessness
- embarrassment
- resentment
- yearning (to be free of the burden)
- shame
- disbelief

And probably many other emotions not listed here.

We will be covering these emotions in more detail throughout the course, but it's important to begin thinking of grief in these broader terms at the outset in order to increase your understanding of those who are going through the process. Too often a crabby old man is seen only as a crabby old man, when his irritability may be his way of grieving over a loss, such as the death of his wife or the curtailing of his independent lifestyle. When we respond only to the irritability ("Well, you don't have to shout at me; I'm just trying to help"), we are likely to escalate his irritability.

We are much more likely to foster the healing process when we respond with empathy: "It seems like you're having a rough day today. Would you like to sit and have a cup of tea with me?"

Elisabeth Kubler-Ross and the grieving process

Elisabeth Kubler-Ross was a psychiatrist who was born in Switzerland, but lived much of her life in the United States. In 1969, her book 'On Death And Dying' was published, and for the rest of her life she was famous for helping people understand the process of grief that people who are dying typically go through.

As you review the five stages below, try to understand each stage both from the point of view of the person who is dying and that person's family members or carers. The five stages of grief Kubler-Ross described are:

1. Denial

This is our way of buying time. Essentially it means: *I'm not ready to face this yet*. By insisting it can't be true, we are giving ourselves a chance to adjust.

It is easy to understand how someone with terminal cancer might find their diagnosis hard to believe, but family members often go through the same process, especially when they live far away. A daughter in London, for example, may be unaware that her mother in Manchester has dementia because her father has managed to cover up her disability in phone conversations. When her father needs assistance and can no longer hide the fact, the daughter's first reaction may be disbelief: "She sounded fine on the phone last week; you must be exaggerating!" Part of the reaction is from shock – *I thought everything was fine; how can this be?* – but part of the reaction is from grief – *I'm not ready to lose my mother. I don't WANT this to be true. It CAN'T be true.*

When you are a professional carer who understands the disease process or a family member who has witnessed the deterioration of their mother's abilities over time, it can be frustrating to deal with a family member who is in denial. But we all grieve in different ways and at different rates. It's important to respect the emotional pain of the person who denies reality until they have gathered their strength and are willing to face a difficult truth.

2. Anger

Anger is often the first step in coping with a terrible loss – *This isn't fair; I'm going to fight this!* In one sense, anger is good because the person who is dying is trying to take charge in whatever way they can. They may not be able to stop the course of the disease, but, by golly, they're going to control what treatment they are given and how they will spend their remaining days. Unfortunately, anger is very often misdirected. The person is frustrated and angry at what they CAN'T control, and in feeling helpless, they take their anger out on everyone else around them. The same may be true of carers who feel inadequate to help and perhaps saddened for their client's unfulfilled dreams for retirement. Life isn't fair, and some of us rail against it as if that might make a difference.

It should also be noted that anger may be delayed. Sometimes people will seem to cope amazingly well after the death of a spouse, for example. They throw themselves into their work and never seem to miss a beat. It may not be until years later when they retire and suddenly become full of anger and irritability because their spouse is not there that they finally begin to grieve.

3. Bargaining

The third step is often more subtle. Kubler-Ross suggested dying people often bargain with God: "If you help the doctors to discover a cure for me, I will go to church every Sunday and never smoke again." But in reality, we make bargains often in our daily lives: "If I can get through this traffic jam and get to work on time, I promise I will start out earlier tomorrow." We also bargain with the people we are caring for: "Please don't make a fuss about your bath, and I promise I'll give you a backrub when it's over."

4. Sadness

This is the emotion we recognise most clearly with grief, and it is perhaps the most authentic and valid response. It IS terribly sad for someone to bear such a loss, but there is no right or wrong length of time to be sad. In years past, families typically mourned for a year – and wore dark clothing throughout that time – when a family member died. There was some logic to it – if family members could celebrate each of the holidays without their loved one (birthdays, anniversaries, Christmas, etc) it was thought that the next year might be easier. In reality, grief isn't particularly logical. Some people seem to return to cheerfulness in a few months; others take years. People think they are doing just fine and then some little incident may set off a flood of tears. The bottom line is, when someone is sad, they need comforting.

Some people truly become clinically depressed and need counselling and treatment. We will cover this more later in the course.

5. Acceptance

The desired end result of grief is acceptance – *I can live with this.* People who die in peace are those who have accepted the inevitability of their own death and are 'living' their final days as well as they can. Family members and friends who have worked through grief to acceptance see that, in spite of their loss of a loved one, they can go on living. This is where our souls find peace. What will be will be. We all endure tragedy in some form. If we are lucky, we are also the beneficiaries of many good things in life – love, joy, laughter, family and friends, wonderful memories, treasured experiences. At the end of life, we count our blessings. (That does not mean, however, that we have to accept terrible diseases without continuing to fight for a cure, or endure neglect without striving for access to quality healthcare for all.)

People remain individuals

These five stages are not written in stone.

- No two people pass through them identically;
- Some people skip stages, repeat them or go through them in a different order;
- And not *everyone* will reach the stage of acceptance before they die.

Nevertheless, knowing these stages of grief is useful for identifying patterns in our behaviour and for creating self-awareness. Although Dr Kubler-Ross was focused on people who are dying, these stages are often apparent in anyone experiencing a loss of any kind.

Anticipatory grief

'Anticipatory grief' is recognising the loss that is coming. This often happens with people with Alzheimer's disease and their families. The person is incapacitated and unable to care for themselves for a long time, sometimes many years, before they die. So the family – and the person with dementia, for as long as they maintain awareness – goes through this ongoing adjustment to new losses in the person's abilities for years. When the person finally dies, it may be a relief that the suffering has ended, but it may also trigger the grief response to begin all over again. This may also be true of certain cancers, Parkinson's and other chronic diseases.

Mini summary:

Benefits of understanding the five stages of grief:

- It forces us to recognise that grief is not just about being sad, and
- It causes us to look at grief as a process, not just a static, time-limited state.

Part 2: Who Loses What?

Physical losses in ageing

The following are typical physical losses nearly everyone faces to some degree as they age. If you are ageing, which are the most difficult for you to adjust to? If you are still young, which ones do you fear?

- **Visual acuity.** Especially seeing small things clearly and the ability to see anything clearly when the lights are low.
- **Hearing acuity.** The ability to hear beginning and ending consonants clearly, the ability to hear high notes in music and women's and children's voices.
- **Hair.** It tends to thin on the head, but in men, grows rampantly in noses and ears and on eyebrows – how unfair is that?!
- **Skin elasticity and tone.** Skin tends to wrinkle and sag.
- **Flexibility.** Joints tighten and get creakier unless a constant effort is made to maintain them.
- **Stamina.** Except in people who keep exercising regularly, the ability to move quickly and for lengthy periods diminishes. Constant exercisers may also find that they sustain injuries over time.
- **Quickness of thinking.** Most people do not lose their ability to think clearly with age, but may take longer to formulate answers or learn new information – perhaps, in part, because they already have brains filled with a lifetime of knowledge and experiences!
- **Healing capacity.** As people age, their skin tends to be slower to heal from a wound and they take longer to 'bounce back' after an illness.
- **Taste and smell.** As people age, their ability to distinguish smells is often compromised, and they may be unaware of their own body odours. Since taste is closely related to smell, food often tastes bland to older adults. The medications many older adults take may also interfere with their ability to taste food fully.

You may think that most of these things don't matter much, and often they don't, but think of some of the consequences:

- If you can't hear children's voices easily, you may not be able to communicate effectively with your grandchildren. You may also have trouble making sense of friends' conversations in a crowded room, or understanding TV programmes.
- If you can't see clearly (and many older people have *severe* vision impairments), you may not be able to enjoy favourite pastimes like reading or watching TV. You may also have to give up driving, which means a loss of independence.
- If you can't taste your food, mealtimes become less appealing.
- If you don't heal quickly, you may live in fear of illness or injury.
- If your joints ache, you may not venture out much.

Can you think of any other consequences?

Lifestyle losses

When people are physically or mentally disabled, their world almost always shrinks. Even going to the supermarket can be a physical challenge if you need to use a wheelchair, and people with Alzheimer's disease tend to get very overwhelmed by aisles filled with thousands of choices, so even choosing a loaf of bread becomes a challenge. Going out for the essentials is such an energy-draining task that going out for pleasure isn't even considered.

Family carers

In many cases, the family carer is the one who faces the greatest lifestyle challenges.

Let us imagine an elderly couple named Harry and June...

Harry is diabetic and has high blood pressure and heart disease. He has had bypass surgery following a heart attack, and is doing okay, but his health is still fragile, and he is quite fearful of having another heart attack. June is 10 years younger than her husband, and has always been healthy, but the stress of caring for Harry is taking a toll on her mental health. Harry has always loved sweets, so June is constantly battling with him to eat a healthy diet and keep his blood sugar under control. They used to eat out a lot with friends, but Harry is no longer interested in going out because he can't stand watching his friends load up their plates with foods he can't eat. Harry and June always loved travelling and took several trips a year. Now Harry is fearful of having another heart attack when he is away from his doctors, so they haven't gone away overnight anywhere for two years. June is feeling confined and trapped. She has thought of taking an art course at the community college, but it just seems like too much effort.

If you were June, how would you be feeling?

Chances are, you would be feeling:

- Resentful – over lost dreams of what you had hoped retirement would be, about what you perceive as Harry's unreasonable fears, at being confined and not being able to do the things you want to do.
- Frustrated – over your perceived inability to change your current life.
- Exhausted – emotionally and physically, because you are not only doing all the household things you once did, but arranging for help to do the things Harry can no longer do.
- Guilty – for perceiving yourself as selfish for feeling this way.
- Sad – that this is what life has become.

Now let's imagine another scenario...

When a spouse has dementia

Bill is the faithful husband of Betty who is in the mid-stage of Alzheimer's disease. Betty is generally good-natured, but has become very clingy – she follows him everywhere. She no longer knows how to dress or bathe herself and Bill finds it takes nearly two hours each morning to do those tasks with her. She is still able to go to the bathroom herself, but there have been a few incidents in public bathrooms when Bill had to send someone in to check on her. That has made him wary of going out for anything other than very short excursions. Bill has learned to cook and do the laundry and cleaning, but he finds running the household single-handedly AND taking care of Betty is exhausting. Lately he has had some heart pains that have caused him additional worry.

The worst part for him, though, is their utter lack of a social life. Betty gets very anxious in crowds, so they avoid going to shopping centres or to church. Two of their close friends have moved away, another died, and one of Betty's closest friends says she can't bear to see Betty this way, so she no longer visits at all. Bill's male friends don't know how to talk to Betty, and Bill can't go fishing with them because he has no one to care for Betty while he's gone. Bill and Betty's children live a long way away and don't really have a sense of how disabled Betty is; Bill is trying to keep them from being burdened by her condition. Betty used to be Bill's best friend and favourite companion, but now she can no longer hold more than a simple conversation and is completely dependent on him. He feels terribly alone.

If you were Bill, what emotions would you be feeling?

Chances are you would be feeling all of the things that June felt above, and more. One of the profound differences between being a carer for someone who is dying of cancer, for example, and someone who is dying of Alzheimer's disease, is the loss of companionship noted by Bill.

The person who is dying of cancer can still discuss potential treatments, make plans for how they want their affairs (and funeral) to be handled, and still share their love. The person with Alzheimer's disease still feels all the emotions of any human being without cognitive losses (which is important to remember), but as the disease progresses, usually has severely compromised communication skills – an inability to verbalise thoughts, assist with decision-making or discuss an issue reasonably. The sense of mutuality and reciprocity is often lost when a spouse has Alzheimer's disease or some other form of dementia.

In her booklet, 'Managing Grief And Bereavement', Edna Ballard quotes carers:

- "I feel like my life is on 'hold.'"
- "I keep thinking of all the plans we made before that are now just empty dreams."
- "Friends and family say I am lucky as I still have him with me. He hasn't recognised me in six years!"

Ballard elaborates on that last one by explaining that when a person dies, as difficult as that is, society somehow has rituals and expectations. They will gather round and envelop the bereaved person and help them through that grief. Yet, family members who are taking care of someone with Alzheimer's will often say: "I have a hard time making people understand that even though I still have my husband,

if he hasn't known me for six years, I *don't* have my husband. People have a hard time understanding that though he looks the same, he's not the same individual."

Spouses of people with dementia often mourn the loss of the person as they once knew them – the person their spouse once was – long before that person dies. Professional carers often get to know that spouse only when their condition is advanced – and accept the person just as they are. The acceptance is good, but it's important to be sensitive too, to what the well spouse has lost.

If the marriage was never particularly strong in the first place – or was a second recent marriage that had little time to strengthen – the resentments and other emotions may be exaggerated and the relationship severely tested.

Some families are blessed with marvellously supportive children, but their role is not easy either. If you have had a special bond with your parents and have enjoyed the security of being your parents' children, reversing roles and stepping into a position of authority and responsibility for their care is foreign and awkward, and most of us stumble a few times in the process.

The disabled person also grieves over the role change

In the case of today's older men – many of whom were raised to 'protect their women' – there is often a deep sense of loss that they can't continue to fulfil that role. There was a poignant part of former US President Ronald Reagan's letter to the world when he was diagnosed with Alzheimer's disease, in which he expressed his sorrow over what his wife Nancy would have to go through as a result of his deterioration. He recognised the likely emotional cost she would experience as a result of caring for him, and wished he could prevent it.

Donna Cohen, in her book 'Loss Of Self', describes a man who wanted his wife to understand how much it hurt him not to be able to care for her needs. He knew he was loved by family and friends; the problem was "not that I have no one to share my burden. It is that I have only my own burden to bear." He mourned his former self who could take care of not only his own needs, but the needs of others.

When a person needs professional care

Eventually, many people with chronic diseases, such as problems with the heart, lungs, or kidneys; various forms of cancer; or people with Alzheimer's disease or mobility problems, decide (willingly or not) to move to a residential care community (assisted living, nursing home etc). There, they face a great many other losses. If they are married, one or both partners are likely to feel some of the following:

- **Loss of spouse, companion, sexual partner.** When spouses are separated, even if they visit each other every day, both tend to feel an enormous void. Many retired spouses spend virtually every hour of their days and nights together. The loss of the constant presence, the warmth, even the smell of their loved one can be devastating. If they have had an active sex life, the new problems related to where and when continued intimacy can be possible also increase discomfort.

- **Loss of friends.** Often the well spouse has spent years caring for his/her spouse before placing him/her in a long-term care community. Often, friends have fallen away during those years, especially if the care-receiver has dementia. Friends often have a hard time relating to the changes wrought by dementia, so they say things like, “Call me if you need me,” and couples never see them again. Most family carers are terribly isolated. When their spouse is placed in a long-term care setting, it’s not easy to pick up the pieces of broken friendships. Moreover, the person in the long-term care setting has suddenly been left alone among strangers where they must make new friends. If their communication skills have been damaged by dementia, this can be especially difficult.
- **Change in social status.** Even as a care-receiver, the person had status whilst in their own home. They retained some sense of power and control. In a long-term care setting, it is the staff who hold all the power, and sometimes they can wield it insensitively.
- **Decreased mobility.** There is no doubt about it: the person who is living in a long-term care setting is simply not as free to move about as they once were, even if they are physically capable of doing so. They may be too far from their former coffee shop to walk there and they are unlikely to have control over the home’s schedule for outings. At the same time, family members who are willing to help take them to the doctor, may be less willing to make time in their schedule to take them out to the movies or another social event.
- **Loss of privacy.** Every long-term care setting of quality will tell you that they respect the privacy of their residents. But the reality is that they have access at all times to residents’ rooms, and they record the most intimate details of residents’ lives, including the frequency and consistency of their bowel movements. Well spouses who visit may find it difficult to have an uninterrupted private conversation, much less intimacy, with their loved one.
- **Changes in relationships with family and friends.** Other family members and friends who visit someone in a nursing or care home may also feel awkward. When they visited the person at home, they often had a specific role – to fix a meal, mow the lawn, help pay bills. Here, they have nothing to do but make conversation, and when the person has dementia, that can be especially difficult. They need help from the staff to learn how to have satisfying visits.
- **Loss of home, familiar environment, community and reduction of personal space and belongings.** When a person moves to a long-term care community, he or she is giving up everything that was familiar and provided a sense of belonging (in some cases for 50 years or more), for an environment that is completely unfamiliar and where it may take a long time for them to feel they belong or fit in. In addition, they are usually forced to cram what they can of a lifetime of collected furniture, knick-knacks, heirlooms and assorted treasures into one small room. Often the well spouse also moves at this time into a smaller house or flat, and also shares these losses.
- **Change in routines and loss of decision-making power.** A loss of control over personal choices, routines and lifestyle habits is very hard. Quality long-term care homes pride themselves on offering their residents choices over what to eat and when to get up in the morning, but, as with the issue of privacy, it is the staff who have the real control. They set the menu, plan the activities and make most of the rules (or are bound by government regulation).

A special challenge: Loss of identity

Perhaps the biggest loss many older adults endure is a loss of identity, and with it, self-esteem. When you move to a new city as a working adult, it takes time to adjust, but you meet people through work, your children's schools, your faith community or the organisations you join. You have many opportunities to be seen by others as a competent person with talents and skills – as a valuable addition to the community. When you move to a retirement community or care home, particularly if you move because of physical disabilities, the confidence you had as an independent person can easily be lost. The staff and other residents don't know you for your past, but for the conditions and circumstances that lead you there. You are 'a case' not a multi-talented, fascinating human being. And if you can no longer physically or mentally do what you once did, that is a further blow to your ego. One of the chief reasons people with Alzheimer's disease become angry is their utter frustration with their inability to carry out tasks or carry on conversations as they once did.

At the same time, the well spouse has often devoted so much of their life to providing care that they no longer see themselves with any other identity. Now that their partner has been placed in a long-term care setting, with other people providing their care, the well spouse has no idea what to do with their life. Others may think they must feel tremendous relief and freedom; instead all they feel is a tremendous void.

There's more to the story

Of course, many older adults are blessed with terrific support from family, friends, faith communities, support groups, government organisations and other entities.

Furthermore, any residential care home worth considering will do many things to help new residents and their spouses ease through these changes and to provide compensating activities; indeed, one of the chief advantages residential care has to offer is the multitude of opportunities to interact with others and overcome social isolation.

Nevertheless, if we fail to acknowledge the real sense of loss people may be feeling, they may be resistant to appreciating and making use of what is on offer.

Watch for signs of depression

Given all these losses, it is not surprising that some people who are grieving actually develop clinical depression. Psychologists talk of 'grief work', because grief must be worked through; it doesn't just happen. A person who can't move beyond a profound and painful sadness often has unresolved conflicts based either on the past (guilt over what they 'should' or 'shouldn't have done' in the care of their loved one), or the future (they quite literally don't know how to go on).

Seeking professional counselling is unfortunately still not well accepted in some circles, but chaplains, social workers and trusted friends can often help the troubled person by simply listening well – with empathy, without judging or offering solutions; just listening. (We'll cover this in more detail in the next section.) Social workers and chaplains are also available to counsel families during the dying process. Many people also benefit from participating in an Alzheimer's support group through their local community.

Even though we have become quite good in recent years at treating depression with counselling and anti-depressants, most people who are depressed don't seek help. Therefore, it's important to watch for signs, such as people who:

- Are sad, anxious, feel 'empty', weighed down, heavyhearted
- Sleep too little or too much
- Exhibit changes in weight or appetite (Who feels like cooking?)
- Exhibit a loss of pleasure or interest in activities
- Feel restless, anxious or irritable
- Have trouble concentrating, remembering or making decisions (People who are depressed are often mistakenly considered to have early signs of dementia, and may indeed have them if they are malnourished.)
- Show persistent fatigue or loss of energy
- Express feelings of guilt, hopelessness or worthlessness
- Have physical symptoms that don't respond to treatment
- Express thoughts of death or suicide

Always report your suspicions of a person's clinical depression to a supervisor, nurse or doctor so that formal evaluation and treatment can be given.

Part 3: Ideas For Helping People Cope With Grief

The ideas that follow apply to multiple situations, many of them related to what friends and family members can do. If you are a carer in a long-term residential care setting, think of ways you can use these ideas:

- for family support groups,
- to build community among staff and family members, or
- as part of a community outreach booklet or talk to share with the public.

General guidelines for comforting others

- Acknowledge their feelings and the difficulty of what must be faced.
- If you would feel the same in their shoes, tell them.
- Ask how you can help.
 - Solve the problem if you can.
 - Experiment with alternative solutions.
 - If there is nothing that you can do; commiserate.
 - Sit still and listen; sometimes the best and most helpful thing is simply to be there.
- If the person is open to it and it's appropriate; hold their hand, give them a hug.
- When the person has exhausted their need to express their feelings, help them to move on by offering something pleasant to do.

Things you can do and say to be helpful to care recipients:

- Tell them that you're sorry they seem to be sad today.
- Reassure them that they are loved, valued and safe.
- Tell them how much you will miss them when they're gone.
- Give them something physical to hang on to as a reminder that they are loved (card, photo, religious item/picture, medal, a heart cushion, etc).
- Do something special with them – distract them from their sorrow.

*It's not easy taking my problems one at a time
when they refuse to get in line.*
Ashleigh Brilliant

Acknowledge the person's mortality

When a person with a major disability, or who is dying, indicates they want to talk more deeply about their condition, take the opportunity seriously. Many people feel uncomfortable about such discussions and therefore deflect them: "Oh, John. You're going to outlive us all. Let's not talk about that now." In reality, usually all that is being asked of us is to listen. That is a courtesy we can all perform.

As we've noted, grief related to Alzheimer's disease is often anticipatory, as in, it begins many years before death. Only in the early stages can the person who has the disease verbally express their grief over what is happening to them and over the effects of their illness on others. At this point, family members and friends are often reluctant to discuss the future, either out of a desire to 'protect' their loved one, or because they are still in denial themselves. But here, too, the impulse to make light of the person's concerns should be resisted. A year or two later, when family and friends are ready for the end-of-life discussion, it may be too late.

At the same time, we are probably mistaken if we doubt that people with later-stage dementia do/can mourn. When they show us their anger or tears in the late stages, we rarely attribute it to grief. Who knows how wrong we might be?

What NOT to say to someone experiencing anticipatory grief

*"When you are unhappy or dissatisfied,
is there anything in the world more maddening
than to be told that you should be contented with your lot?"*

Kathleen Norris

- What disastrous things have well-meaning friends said when you were feeling low?
- What are some of the things you know are not helpful to say when someone is grieving a serious loss?

How about the following:

- **"How is Mary doing?"** (Fill in the name of the care recipient.) Of course it's nice of you to show concern and interest, but be aware of two things:
 - 1) If the answer is, "About the same" (which is often the case when someone has Alzheimer's disease), the carer may see that as unbearably sad, but not want to admit it;
 - 2) Regardless of the care recipient's condition, the carer wants to be asked, "How are YOU doing?" Recognise that his or her journey is not easy.
- **"You have to take good care of yourself, because if you aren't in good shape, you won't be able to help Mary."** A carer may think: *Is that all that matters? Is 'carer' my only identity now? Shouldn't I take good care of myself just because I'm a valuable person and I'm worth it?* Providing care CAN be all-consuming, but carers still want to be seen as individuals with their own needs and interests.

- **“Call me if you need me.”** Very few people are willing to admit they are needy or vulnerable. Instead of asking, just be there for the person grieving. Show up. Make yourself available. You may be rejected, but give yourself credit for trying, and then try again another time. Don’t give up. And don’t feel you have to present them with gifts or casseroles (these can sometimes create guilt for the recipient – “Oh, you shouldn’t have.”); your presence is much more important than your presents. Never let the lack of a gift keep you from visiting.
- **“You have to be strong,” or “You are holding up well.”** Uh-oh, that means the grieving person can’t lean on you for support, or show you their weaker moments.
- **“You don’t mean that,” or “You shouldn’t say that.”** When someone is grieving, they may say a great many things against God, fate, loved ones, the medical community and themselves that they probably wouldn’t say in less stressful times. Give them a chance to rant without judging.
- **“Oh, I know how you feel; when Fred was dying, I . . .”** Focusing on what you have been through demeans the grieving person’s loss. The exception to this is one-upsmanship in relation to embarrassing moments. Many of us have made fools of ourselves whilst grieving. When someone expresses their mortification over bursting into tears at an inopportune moment, and you can top it, do so. Then laugh together. Laughter is an effective lubricant for the passage through grief.

What NOT to say when the loved one has died

- **“It’s time to get on with your life.”** What right do you have to determine how long another person should take to work through their grief?
- **“It’s God’s will. At least they don’t have to suffer anymore.”** (And other moral platitudes.) Where is the comfort for the grieving person in those statements?
- **“John, how are you doing? Did you see the game last night? How about United’s goal?”** Don’t change the subject. Don’t avoid using the name of the person who is deceased or acknowledging the continuing grief of family and friends. The bereaved person not only has a need to validate the loss by talking about the person who is gone, but will be appreciative if you continue to remember that the loss will be especially painful during holidays and on special dates (anniversaries, birthdays). You don’t have to be afraid of *reminding* the person of their loss; they are already thinking about it.

How to be a good friend through someone’s grief

A hundred years ago, most people knew what to say and do to comfort the bereaved because death was commonplace and deathbeds often well attended. Children died frequently in childhood; women died frequently in childbirth; most people did not live to a ‘ripe old age’. Protocols for mourning were carefully spelled out in women’s magazines and etiquette books, and nearly everyone, unfortunately, had plenty of practice. Times have changed, but the best advice hasn’t. There are two things anyone can do:

- 1) **Be there.** Show up. Send cards and notes. Help with ordinary tasks. (See below.)
- 2) **Listen.** Remember that listening is about understanding the other person’s message. It is NOT about waiting for your turn to talk. One of the reasons people don’t feel able to call or visit

someone who has recently been bereaved is that they don't know what to say. So just admit it: "I feel awkward; I don't know what to say, and I'm afraid of saying the wrong thing. But I'm here because I care. I'm willing to listen to anything you feel like saying, and I'm willing to just be here in silence with you. I can't undo your loss, but I can be here."

Help with ordinary tasks

Grief often immobilises the bereaved. Even simple tasks can be overwhelming. Chances are there are many ways you can be a good friend and pitch in to help – mowing the lawn, taking the car in for a service, paying bills, writing to insurance companies etc. **Ask the person what things they're having trouble facing and offer concrete help.**

Don't overlook basic errands. For example, if you're going to the supermarket or the dry cleaners, call the person and say: "I'm going to the cleaners – do you have anything I can drop off?" or "I'm going to the supermarket – is there anything you'd like me to pick up?" Many people will hesitate to ask for something specific because they don't want to be a burden, but it's easier to accept your help if you are going anyway.

Be persistent. Our society makes such a big deal of independence that many people have a hard time accepting favours from others, even though an interdependent community is a much nicer place to live. You may have to offer to pick up groceries a dozen times before a person actually accepts.

Be proactive. We noted above that casseroles aren't necessary, but if you enjoy cooking, drop one off (in a non-returnable dish so that the person doesn't need to worry about getting it back). If you're a bad cook, ask when it might be convenient to bring over a takeaway from a favourite local restaurant.

Sometimes people are slow to admit they are feeling low.
When people in a tough situation say, "Oh, I'm fine," remind them that
"FINE is code for Frizzled, Insecure, Neurotic and Exhausted."
Then ask what they would most like from you right this minute.

Send cards and letters

One thing anyone can do is send a note expressing concern. Before a loved one's death, notes are sometimes better than phone calls because they don't interrupt a carer's schedule and they can be reread as an ongoing reminder of your warm thoughts. But most people struggle with what to say, so here are a few suggestions:

- **Purchase a greeting card.** When a carer is mourning in 'anticipatory grief', there are many appropriate cards, such as 'Thinking of You'. When a person has died, every store offers a choice of sympathy cards. There is a caveat here though – never send a card with just your signature. Add at least a line or two in your own words, even if it's just: "I don't know what to say at this difficult time in your life, but this card expresses my feelings for you."
- **Brevity is not a shortcoming.** A pretty note card on which you have scrawled only: "I am so sorry for all that you are going through. Please know that my thoughts and heart (or, if you are religious, my thoughts and prayers) are with you," is far more welcome than you might imagine.
- **Don't be afraid to use humour.** Laughter is one of our best coping mechanisms. It tends to pull us out of our difficulties and give us hope, even if only for a little while. Don't be afraid to send a funny friendship card or enclose a joke or funny photograph you think the person might enjoy. You can include a note acknowledging that you know things are tough, while still hoping that the enclosed bit of humour will brighten the person's day.

Part 4: Remembering The Person Who Has Died

Ideas for what to write to the bereaved person who is mourning

- **Describe what traits, characteristics, or interests you enjoyed about the person who has died.** You don't have to go overboard: "Your father was stubborn and opinionated, but he was also a man of integrity and intelligence with passionate beliefs. I admired him." That's true, but not soppy.
- **Describe specific events that you remember warmly and which may stir up the same or similar memories in the mourner.** "I remember our trip to the Lake District," or "I remember his hilarious stories of visiting his uncle's farm and being terrified of the cows," or "I remember how she loved to play the flute."
- **Describe the person's career or community accomplishments.** "The Christmas market will never be the same without him," or "She will always be my favourite teacher."
- **Describe the love of the person who has died for the person you are writing to.** "I know your mother was proud of how you raised your children under such difficult circumstances," or "Your father so loved to talk about his son, the journalist."
- **Even if you never knew the person who has died, you can sympathise with the loss of the person left behind.** "I know these last years have been difficult for you and that you feel uncertain about the future. Know that I think of you every day and send my thoughts of love and support."

Remembering the person who has died in a residential care setting

In some nursing homes and assisted living communities, death is covered up and the body is whisked away without acknowledgment in a misguided effort to protect the residents' feelings. In reality, acknowledging deaths and giving residents and staff a chance to mourn is highly valued by residents, staff and family members. Even residents with advanced dementia, when given the chance to sit by a deathbed or attend a memorial service, are usually amazingly sensitive. It seems we all want to believe that when we die, we will be remembered and missed.

How a person is remembered can take many forms and it is not our position to tell others what is right in their situation. Obviously, family members may have their own strong feelings. Religious practices and infection control issues must also be respected. Nonetheless, here are a few suggestions of ways to honour the person who has died.

Eulogy cards

Often people resist writing a note to family members and friends who are mourning because they don't know what to say. One way to overcome this is to place a notice in a prominent place, such as a reception desk, that says something like:

"We are sad to announce that Mary Jones died on Thursday afternoon. A memorial service is planned for Sunday at 3pm. If you would like to contribute your thoughts to the service or give a note to her family, please fill out one of the forms below or simply drop your condolence card in the box below."

The form would list the person's name at the top and leave a series of unfinished sentences with blanks. Residents and friends could fill in as many or as few as they liked. Here is an example:

Our friend _____ (fill in blank with person's name) will be missed.

S/he was known for _____

We all admired his/her _____

The thing s/he was proudest of her/himself for was _____

The one thing I will miss most about him/her is _____

If I could bring him/her back for a day, I would tell him/her _____

I would like this tribute read at his/her memorial service.

I would like this tribute to be given to his/her family members.

Signed _____ (your name)

In-house memorial services

An in-house memorial service provides an opportunity for staff, family members and residents to formally pay their last respects to residents who have died and to provide closure to those relationships, particularly if going to the actual funeral would be a logistical hardship. The memorial service confirms that remembering the deceased is an integral part of your community's life. Participating residents can take comfort in the knowledge that they, too, will be remembered when they die.

Here are some ideas for what to include in a memorial service:

In preparation for the service:

- Place a picture of the deceased resident next to the notice of when the service will take place.
- Try to schedule the service at a time when staff members who had the most contact with the resident can attend.
- Give family members an opportunity to suggest elements in-keeping with the deceased resident's desires, such as a favourite hymn or bible reading. Perhaps they are also willing to share their own feelings, stories or photographs during the service.
- In bulletin form, provide a brief written life history of the deceased, gathered from their family, or from staff and residents' memories.
- Set up the room with chairs in a semi-circle so that attendees partially face each other. This facilitates group interaction and provides a stronger feeling of connectedness.
- Invite all families and staff to attend (as well as any hospice staff who may have been involved).
- Recruit an appropriate priest or layperson to lead the service.

During the service:

- Place a large, recent, clear photograph of the deceased on a draped table with a bouquet of flowers at the front of the room. If a number of participants have dementia, you may want to pass the photograph around the room to help residents remember the person who has passed away.
- Keep the service itself relatively short and simple, especially if a number of the attendees have dementia, but include whatever hymns, prayers or other rituals are appropriate to that person's faith. If the person was not part of a faith community, simply substitute an uplifting poem or other readings and songs.
- Encourage staff and residents to express their feelings and memories and don't be afraid to laugh or cry as a group or individually. This is the time to share the 'eulogy cards' described above.
- Be sensitive to others' emotions and feelings. Note where follow-up may be appropriate.
- After the service, serve refreshments. Most funerals have some time for socialising afterwards.
- Consider a lasting memorial with an appropriate ritual. Perhaps you want a wall of remembrance with small plaques for each person, or perhaps you want to plant trees, shrubs or flowers in memory of each person who has died. Sometimes family members choose to give a particular gift, such as a bench to be placed in a peaceful spot in the garden.