

Anticipatory Grief

Information for Patients and Families Coping with End of Life and Medical Assistance in Dying (MAID)

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Anticipatory Grief

Anticipatory grief or preparatory grief is different than the grief experienced after a loss. It is experienced before death and may begin for a patient and their family at any point from the time of receiving a serious diagnosis, up until death occurs. Anticipatory grief is a natural, expected experience. Everyone's grief is unique and different. There is no one way or right way to grieve. When facing death, grief can be confusing and difficult as you and your family try to balance roles, responsibilities, relationships, important tasks, and adjusting to your new reality. Some common feelings that may be experienced are anger, fear, anxiety, guilt, regret, joy, relief, peace, sadness, and love. You and your family may experience physical reactions in your grief—achiness, stomach pains, or nausea for example. Losses in the past, losses currently happening, and losses yet to happen can all prompt feelings of grief.

This booklet provides information about some of the common thoughts, feeling, reactions, and experiences that may occur as a result of anticipatory grief and ideas for coping with them. Sometimes it is enough to know what is happening is normal or to be expected. Other times, patients and family members do not understand what is happening for each other. More information and helpful suggestions can increase their ability to cope, communicate, understand, and support one another.

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A Patient's Perspective

As a patient deals with a diagnosis, serious illness, and death, they grieve the many losses they face—past, present and future. In their grief they will experience a wide range of thoughts, feelings and responses in trying to come to terms with this new reality. Due to the wide range of normal reactions, patients may feel worried and overwhelmed. It often helps to know what to expect and that these reactions are a normal part of anticipatory grief. Patients may also spend time reflecting on their life, and this can bring insights into what is most important and help bring clarity to how they wish to spend their remaining time.

Social

As a patient's roles and responsibilities change, they may have feelings of self-consciousness and low self-esteem. They may experience social isolation as their health status deteriorates and they no longer have the energy or ability to participate in activities and relationships as they used to. Former activities and interests may no longer be available to them. Some patients feel indifferent to social contact and withdraw; others need connection with important relationships, but find it difficult to ask. Patients may find that people around them may have unrealistic expectations about both their physical capabilities and emotional status.

Physical

Adjusting to the continual changes in daily activities and the loss of their former lifestyle will likely increase the patient's fatigue and drain already low levels of energy. It is important for people to pace themselves and save their energy for the activities that are most important to them. The loss of independence, both physical and personal, is difficult.

A Patient's Perspective (continued)

Emotional

Patients may experience a wide variety of feelings, which may occur as moments of intense emotion. Anger, sadness, depression, and guilt are common and natural to feel. Patients may be quite irritable, and have low frustration and tolerance levels. Current grief may resurrect old feelings, issues, or unresolved conflicts. They may experience anxiety or fear about self and others, as well as concern for the future well-being of their family.

Thoughts

The stresses that patients experience during this time may interfere with how well their mind functions. Both concentration and memory can be poor and decision-making becomes difficult. At times, patients have a sense of disbelief about reality or a feeling of losing control. Also, it is natural to fluctuate between denial and acceptance of the situation. Patients can be preoccupied with thoughts of how they will die, or thoughts about being a burden to the family.

Spiritual

Attitude toward and perception of the changes that are occurring will affect how well patients are able to cope. Hoping for miracles may change to looking for the hope in each day. Patients may question their beliefs, search for the meaning in life or pursue spiritual peace. Time is often spent reflecting on one's life, relationships, regrets, and things one wishes they would have done. Mourning for future hopes, dreams and unfulfilled expectations is a natural and important part of the grief process.

A Family's Perspective

During this time, family and other caregivers will find that they also have a range of responses and emotions. The many thoughts and feelings that arise may be intense and overwhelming and may recur with changes in the patient's condition and care needs. Each member of the family will respond in their own way and it may help to know some of the typical responses.

- Family members may feel as if they are just going through the motions of everyday life. They often try to protect the patient by not talking about the illness or the future.
- Feelings of helplessness and hopelessness may occur with increases and changes in care needs.
- Feelings of frustration or despair about not being able to fix things or control things.
- Feelings of uncertainty due to the unknowns of the journey ahead.
- Shock and numbness can accompany a sudden change in condition.
- Yearning for things to be the way they were before is common.
- Anxiety and fear about three areas in particular are common:
 - carrying on with the necessary tasks of living and caregiving,
 - ability to cope after death, and
 - heightened awareness of your own mortality.
- Loneliness increases as family roles change and the patient becomes more dependent for care.
- Edginess and irritability may arise in your relationships with other people.
- Fatigue is sometimes experienced as sleepiness or having no interest.
- Feelings may show up as physical discomforts or ailments: nausea, headache, stomach ache, etc.

A Family's Perspective (continued)

- Family may feel angry at the cause of the serious illness, the healthcare workers or the thought of the person dying and leaving them alone.
- Family members may wish they had treated the patient better or fear that they have contributed to their illness. The unknowns of the future are overwhelming and self care suffers.
- Family may also make bargains in seeking a miracle. They may feel guilty for being healthy and offer more care than is realistic, exhausting themselves. It may be hard for them to ask for help.
- As the patient's health declines, family may have conflicting feelings: example, wanting the patient's suffering to end, while not wanting a future without them.
- Sadness is common and may be expressed in a number of ways including yearning for future plans that will not happen.

Coping with Serious Illness

As patients and families deal with a serious illness, they will each find their own way to respond to the circumstances that arise. The following section outlines some of the different responses that may occur. Not everyone will experience all of these responses. Each person's experience will be unique. These reactions may overlap or run together as people try to deal with their situation. Patients and family members are often in different emotional states at different times, increasing the stress for everyone. When patients and families try to understand each other's ways of coping, it may help reduce stress and improve the ability to come together at a very difficult time. It is important for the patient and family to each know their own limits and to ask for help or support.

Different Ways of Coping—Patient Responses

- The patient denies that “this” is really happening: “It’s not true; it’s a mistake.” The truth can be too painful to handle all at once. While the person may start by denying or being in shock, the information will gradually be taken in at a rate, which suits the individual.
- The patient may experience deep anger at fate, asking “Why me?” They may direct their anger at anything and anyone.
- The patient starts to make deals in an attempt to influence fate. Promises of good or changed behaviours are made in hopes of reversing the serious illness or gaining more time. Often the person will keep the bargaining a secret.
- The patient has come to terms with their circumstances and no longer feels overwhelmed or as burdened.
- The patient may be emotional and sad, with a need to express sorrow. Attempts to cheer the person up are unhelpful and may alienate him or her. It is more helpful to acknowledge their feelings and let them know their feelings are valid.
- The patient may gradually withdraw from their present world and be unable to maintain connections due to their illness, declining energy level, or decreased mobility. It is normal for a patient’s social world to become smaller as their illness progresses.
- Each person’s experience will be different, and may include all of these responses, some of these responses, or none of these responses. A person may experience the same thoughts or feelings more than once at different times.
- Patients may focus on what truly matters to them in their remaining time. Examples of this may be expressing love, saying goodbye, asking for and giving forgiveness.

Families of Dying Patients

Caring for a seriously ill family member can be confusing and difficult when trying to balance the patient's needs with those of the family. On the one hand you are attending to the care of the ill family member and maintaining involvement with them. On the other hand you are grieving your own losses and beginning to prepare for life after the person has died. There is never enough time or energy to attend to these opposing needs. While navigating these needs, families may experience the following, in no particular order.

Fluctuating from denial to acceptance of the illness and death

Some denial of reality is healthy and necessary in order to function. It allows information to be taken in at a more tolerable pace, and gives family a break from the emotional stress of a situation. Acceptance of what is happening will not necessarily bring peace.

Meeting the needs of the dying person

As their illness progresses, the patient's physical and emotional needs will change. The task here is to help in the best way possible without taking away the person's control or independence. Do not make assumptions about what they need or feel. Ask before you act.

Establishing a relationship with health professionals

It may be necessary to learn how to be constructively assertive, as well as find a way to deal with frustration. Family and health professional conferences can help to reduce anxiety by opening communication lines and providing direct information. It may help to write concerns down before meeting with health professionals.

Maintaining a functional family unit

When someone is sick, it means that everyone in the family must take on new roles and responsibilities. At the same time it is really important to maintain some normal family routines, as this provides some security in the midst of chaos.

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Families of Dying Patients (continued)

Living with the emotions of grief

During this time both patient and family experience intense swings in emotion. Having information about these feelings and being aware of reactions will help everyone begin to cope. It is important for family to let each other know how they are feeling and what they need. There may also be things that people prefer to discuss with someone outside of the family unit.

Communication

Being able to talk about the serious illness, dying, and death can allow for important end of life conversations. Honesty, openness, and compassion are important during these conversations. It is okay to share stories and laughter. Express love, gratitude and forgiveness. This is an opportunity to say goodbye, and to say or ask about things that are important. This time also allows for important practical matters to be talked about, like funeral plans and the estate of the dying person. Having these important conversations while the patient is able to participate can minimize regrets of things the family and the patient wished they would have talked about or done. Communication will change as the illness progresses and death approaches; eventually communication will include more silence and can be expressed in non-verbal ways like touch.

Anticipatory Grief and Medical Assistance in Dying (MAID)

Choosing MAID as an end-of-life care option can result in many feelings for both the patient and their family. There are no right or wrong feelings. Even if you are very sure about your request for medical assistance in dying and your family is supportive, you may still experience a range of thoughts, feelings, and emotions as you prepare and plan for medical assistance in dying. It is normal to find yourself reflecting on your religious, spiritual, cultural, moral and ethical beliefs and values. Try to make room for these feelings, whatever they may be. Planning and knowing the day and time of death can result in some unique thoughts, feelings, emotions, experiences regarding anticipatory grief.

This may be a difficult time in your family relationships. Blended families, including divorce, separation, ex-spouses, stepchildren, estranged family members, etc. may be part of your family make-up. Everyone will have their own unique way of coping and moving through this journey. Possible tensions, challenges and disagreements can be expected. It does not mean there is anything wrong with you or your family, even if it can feel that way during such a difficult and emotional time. Remind yourself that even the healthiest of human relationships are imperfect. Asking for help is not a sign of weakness, it is a sign you are aware of your needs and taking care of yourself. Reach out to supports such as spiritual care, social work and counsellors. The MAID social worker can also talk to you and your family and offer support.

Disenfranchised grief is a hidden grief you may experience. Grief is not always openly acknowledged or socially supported. Some patients and families talk about feelings of isolation and shame due to the stigma of medical assistance in dying impacted by cultural or religious norms, values, or beliefs. This can be painful and confusing and affect normal grief before and after death. It is important to find someone you trust to talk about these feelings as your grief is what you say it is, and you deserve to be listened to and supported.

Anticipatory grief and Medical Assistance in Dying (MAID) (continued)

The precious time of weeks, days, final hours of life and death can be both one of the most stressful and special times in our lives. There is no road map or “how-to list”. At any moment, you are doing your best to navigate an unfamiliar experience of preparing for medical assistance in dying. Death is never easy, but patients and families commonly report feeling relief once the subject is brought out into the open. Knowing your wishes before and after death can be helpful to everyone. Do your best to be understanding of each other’s unique journey, while also being kind and caring towards yourself. Make room for differences, allowing everyone to decide how much they feel they can be part of this experience and ask for help and seek support from others.

Exploring a medical assistance in dying death:

When thinking about medical assistance in dying, many thoughts, feelings, and ideas may come to mind about what is important during the time leading up to the day of provision.

You may wish to consider:

- Focusing on the people and activities you enjoy and find supportive.
- Visiting special places (family home/farm, places in nature, spiritual places, etc.)
- Talking to your family about your decision for medical assistance in dying and including them as much as you feel comfortable in preparing and planning your death.
- Talking to and preparing children for your death including ways to involve them directly or indirectly.

Consider relationship matters with family and friends such as:

- Expressing love, saying thank you, saying goodbye.
- Forgiving others, asking forgiveness, forgiving yourself.
- Expressing regrets or disappointments.
- Sharing stories, life lessons, wisdom, and memories.
- Sharing life joys, passions, accomplishments.
- Attending to estranged or stressed relationships.
- Having a celebration or gathering with family and friends.

Writing letters, videos and wishing private time with loved ones are ways to share the above ideas. Talking about these matters can resolve anxiety, address regrets, and contribute to peace of mind for you and your family.

Consider practical matters such as:

- Arranging gifts or mementos you wish to leave for family and friends.
- Contacting a funeral home to discuss funeral arrangements that are meaningful to you.
- Taking care of legal concerns such as your Will, estate planning, financial information, etc.
- Providing direction on handling technology (computers, phones) and social media accounts.
- Planning for dependent children, adults, and pets who relied on you for care and support.

You may want to consider involving trusted people in these tasks if you feel comfortable doing so. It is okay to ask for help. Those close to you want to help but often do not know what to do. Think about what you need help with and who you can ask.

Many people find it meaningful and helpful to be actively involved knowing they have only little time left to share with you. It can also assist in their healthy grief and coping after death including knowing they are respecting your wishes.

The above are suggestions based on what other patients and families have taught us about what can be important in preparing for death. Factors like your illness, energy, family circumstances and the time left until your death will impact what you can do. Be realistic in what you can achieve. The Provincial MAID Program can support you and your family in exploring, planning, and completing the things that matter to you.

When someone close to you has requested medical assistance in dying:

It is normal to have different feelings and reactions even if you are supportive of their choice. You may be supportive of the law that allows for MAID but not feel completely comfortable with the person's choice to have MAID. Remember your views are based on your beliefs and life experiences. They might not be the same as your loved one who is choosing medical assistance in dying. You may not always know what to say and do and that is okay. Remember everyone is doing their best during a difficult, emotional, and unfamiliar time.

You may have professional values or religious beliefs that conflict with MAID. If you are strongly opposed to the decision, it may be helpful to find people or professionals, including the Provincial MAID Program who can listen and support you so that you can find ways to be involved in your loved one's experience that are okay for you.

You may feel that the MAID death is coming too fast but may also feel relief that the person's suffering will soon end. Some people describe knowing the day and time the death will occur as surreal. You may be fixated on the calendar and count down the days or hours. If the person or family have decided to not share that the person is seeking MAID, it can feel isolating. Likewise, if there are people who are not supportive of the person's decision to choose MAID, you may feel uncomfortable talking about it or feel like you are having to defend the person's decision.

In the time leading up to your loved one's death it may be helpful to consider the following:

- Ways to spend time with your loved one choosing medical assistance in dying.
- Important conversations about dying and death with your loved one and family.
- How family can come together and support each other through this difficult time (listening with an open mind, not judging, compromising, and being inclusive).
- Important things to say to each other (words of love, forgiveness, thanks, encouragement, understanding, saying goodbye).
- What you would like to know about them that you do not know (story telling) and how you might capture this in person, recording, writing, video, etc.
- How you can support your loved one to complete important tasks they have identified
- Other ways to support them (meals, caregiving, errands, housekeeping, organizing, etc.).
- Your own supports during this difficult time (emotional or practical support or help with planning and communication, etc.).
- Important things to do together (intimacy, sharing stories, visiting special places, celebration/gathering, celebrating special events birthdays, anniversaries).
- Ways to take care of yourself (exercising, meditation, spending time with family and friends, nurturing places (nature), healthy eating and sleeping, journaling, etc.).
- Talking to children about medical assistance in dying and involving them directly or indirectly.

Anticipatory grief and children:

Children can experience anticipatory grief, and like adults, it may be experienced differently for each child. Talking to children about a loved one being seriously ill or dying can be intimidating, especially because parents try to protect their children and keep them safe. The best way to protect your child is to have clear, honest conversations. It is important to make sure the language that is used is age-appropriate, and the conversation occurs in a safe place where the child can ask questions. Expect that the child may need time to take in what you are telling them, and may come back later with more questions.

When a loved one has a serious illness or is dying, children often wonder:

- Can I **catch** it?
- Did I **cause** it?
- Can I **cure** it?
- Who will take **care** of me?

It is important to address these questions, even if the child hasn't asked. Children should be prepared in advance for changes to routines, or changes to roles and responsibilities in the family.

It can be helpful to ask the child what they understand is happening, and let them lead the conversation. If the child asks a question you don't know the answer to, it is okay to tell them you don't know. Be honest with the child about how you are feeling as well.

Medical assistance in dying and children:

Talking to children about MAID is another aspect of dying and death that can be difficult to navigate. The Provincial MAID Program can provide you with resources to help you have these conversations. The Provincial MAID Program social workers can also help.

Dying without MAID

Sometimes, a patient dies naturally before MAID can be arranged, or before their scheduled MAID date. This can be distressing for families in the immediate time before the patient dies, as well as after. It is common for families to believe that their loved one did not have the death they wanted, or had a dying process that they had tried to avoid.

Some reasons a patient may not be able to receive MAID are:

- They do not have capacity to request or consent to MAID,
- Their death is imminent and they die before assessments for MAID can occur,
- Death occurs before their MAID provider has availability,
- They are in a conscientiously objecting facility and are too unwell to be moved to another location to receive MAID (risk and probability of dying during transfer).

Patients and families may find that having conversations about their end of life wishes, excluding MAID, can help alleviate some of the distress if the patient is unable to receive MAID. A patient's wishes, excluding MAID, can be captured in an Advance Care Plan. A template for an Advance Care Plan can be found at <https://www.saskhealthauthority.ca/your-health/conditions-diseases-services/advance-care-planning>.



Additionally, good palliative care can also improve a patient's quality of life and decrease their suffering at the end of life. It is important to work with your health care team so appropriate palliative treatment can be offered until death occurs, with or without MAID.

"Death ends a life, not a relationship. All the love you created is still there. All the memories are still there. You live on— in the hearts of everyone you have touched and nurtured while you were here."

—Mitch Albom, *Tuesdays with Morrie*

MAID Social Workers

The MAID social workers are available to support the patient and family throughout their end of life and MAID journey. The social workers:

- Support patients and families in exploring their experience, needs, goals, and hopes and identify ways to assist them in accomplishing what matters and is possible for them
- Assist with relationships and communication such as talking about dying, death, and exploring ways to express love, gratitude, forgiveness, and saying goodbye
- Offer support in completing identified practical tasks such as funeral plans, celebrations of life, rituals, legacy work, and planning the details of a MAID death
- Provide guidance and support in ways to talk to children and involve them in end of life and MAID

To speak with a social worker, please call or email the Provincial MAID Program (contact information found on the cover page of this document).

Anticipatory grief resources:

www.virtualhospice.ca/MAID

www.mygrief.ca

www.kidsgrief.ca

www.whatsyourgrief.com

www.bridgec14.org (MAID specific information and support)

Maidfamilysupport.ca (MAID specific information and support)

<https://legacyproject.org/resources/activities.html> (legacy work resources and ideas)

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Healthy People, Healthy Saskatchewan

The Saskatchewan Health Authority works in the spirit of truth and reconciliation, acknowledging Saskatchewan as the traditional territory of First Nations and Métis People.

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