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## A Genetic Counselor's Guide to Understanding Grief

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### OBJECTIVES

- Describe factors that affect the grief process
- Compare and contrast different models of grief processing
- Explain the different types of grief that can occur under various circumstances
- Identify symptoms of complicated grief
- Understand grief in the context of the genetic counseling profession
- Describe strategies for genetic counselors to facilitate the grief process
- Recognize cultural considerations concerning grief and bereavement
- Self-reflect on one's own grief experiences

*Grief is a tidal wave that overtakes you,  
smashes down upon you with unimaginable force,  
sweeps you up into its darkness,  
where you tumble and crash against unidentifiable surfaces,  
only to be thrown out on an unknown beach, bruised, reshaped...  
Grief will make a new person out of you,  
if it doesn't kill you in the making.*

Stephanie Ericsson (1993)

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\* Both authors contributed equally to the development of this chapter.

## Introduction

Grief is an inevitable part of life. It can take many shapes and forms. Grief is a normal, natural process, but it can become complicated and a challenge to the sufferer's long-term well-being. Through our patients, we will encounter many types and manifestations of grief. Our role as genetic counselors is not to "fix" grief, but to assist our patients in working through their grief by providing support, normalization, and resources. It is also our role to recognize when the patient or family may need professional assistance beyond the scope of genetic counseling in order to successfully navigate their journey. It is perhaps in this arena of our practice, more than any other, where the "counseling" part of genetic counseling becomes so critical.

The goal of this chapter is to help readers anticipate, understand, and recognize grief in relation to the experiences our patients may encounter, as well as their own experiences. We will discuss the grief process from both traditional and more contemporary perspectives. The different forms of grief and different situations in which it may manifest are illustrated through genetic counseling examples and personal stories. We explore the fundamentals of grief work and intervention, and review literature which focuses on grief reactions in the setting of genetic counseling, including how we, as healthcare providers, react to patient grief.

Often when we think of grief, it is in relationship to the death of a loved one. However, death of a loved one is just one kind of loss we may encounter in our practice. Parents and families experience loss and grief when a child is born with a congenital abnormality, genetic condition or disability. In this circumstance, there may not be a death, but the grief is nevertheless profound as what has been lost is the healthy child they had dreamed of and hoped for. The intensity of grief in this circumstance does not necessarily relate to the severity of the condition. If it is your child that is affected, it is the worst possible thing that could happen. We, as observers, may not understand why the family is so devastated by an isolated cleft lip/palate or Turner syndrome, as in our minds, there are far worse diagnoses. We must not, however, devalue the family's grief reactions nor make judgements regarding their appropriateness. "It could have been worse" or "You can have another child" are **not** helpful words to most parents in the early stages of grieving.

Learning one's apparently healthy baby or child has a neurodegenerative or disabling condition can be a particularly devastating grief experience, as the reality the parents had been living with – a healthy child with a bright future – has been ripped away. Anticipating a death, then living through the loss can both intensify the grief, and also allow one to begin the healing process in advance. Unlike a non-genetic death of a loved one, these grief experiences are complicated by the knowledge that one is at-risk oneself, as in the case of Huntington's disease, or at-risk to have another affected child, as in the case of a recessive or X-linked condition. Perinatal loss, infertility, and making decisions regarding termination of an affected pregnancy represent other unique types of grief experiences particularly relevant in the field of genetic counseling.

The type of loss is just one of the many factors that will influence the grief response, which is a unique experience for each individual (Worden 2008). Was the loss anticipated or unexpected? Were physical suffering or major caregiver responsibilities involved? What was the nature of the relationship – child, partner, spouse, friend, unborn baby? What were the length and closeness of the relationship? Was there unfinished emotional business with the person lost? If the last interaction was angry or otherwise fraught, it can intensify the experience of grief.

How the sufferer works through the grief process also depends upon personality characteristics, level of resilience, past experiences with loss, and coping style (Worden 2008). Some people may find it difficult to express or share their grief reactions, which can be a challenge to healthy coping. People who have trouble dealing with the setbacks of daily life are likely to have a more difficult time recovering from a serious personal loss. Grief is also a bit “sneaky,” bringing even the most resilient person to a standstill. Sometimes being the “strong one” is impossible to maintain when grieving a loss. On the flip side, grief may have the long-term outcome of increasing a person’s strength and resiliency.

Perhaps most predictive of how an individual moves through their grief response, is the level of support and understanding from significant others, family members, friends, support organizations, and the medical community. In this regard, we, as genetic counselors have a responsibility not only to provide support, but to ascertain the depth and nature of the patient’s support system and provide additional resources as needed.

We end this brief introduction with one of our own stories of grief and acknowledge that our personal experiences have shaped how we have come to understand grief, in some measure, both in ourselves and others. Throughout the chapter, we add to our own stories those of patients, friends, family members and colleagues.

### Cecelia's Story

My first encounter with grief was at the age of 11, when my mother died after a 2-year-long battle with breast cancer. Reflecting back these many years, it is very clear to me that I neither understood, nor truly acknowledged that she was gone for several months. The day it happened, my father met me when I got out of school and said “Mom is gone.” I remember stopping in my tracks, and not being able to move, but I did not cry. I chose to go to my campfire girls meeting instead of to the burial site, though I now wish I had not been given a choice. The relatives, the memorial service – part of me wondered why all these people were here, acting so sad. When I went back to school a few days later, I told my friends my mom had died, and their tears were a surprise to me. Ultimately, reality seeped in, a bit at a time – perhaps that was the only way I could handle it then, but eventually, my own tears came in a flood when I finally realized she wasn’t coming back. I have grieved not only my mother’s death, but the loss of all those times and events we were supposed to experience together. My first boyfriend, learning to drive a car, the prom, choosing colleges, getting married, having children. The ache and sadness occasionally return, especially around holidays and special events. It is not debilitating, but it can impact me with some intensity, before settling back into the fabric and rhythm of my life.

My second encounter with loss and grief occurred with the birth of my son, Connor, who has disabilities of unknown etiology. He is now 26 years old. I’ve written about this experience previously (Bellcross 2012) and share a few excerpts below. I also refer the reader to this special series of defining moment essays in the *Journal of Genetic Counseling*. “Defining moments include any personal experiences or events that lead to realization about one’s self as a genetic counselor” (Veach and Leroy 2012, p. 162) In these essays, genetic counselors share many personal experiences of grief and loss and reflect on how it impacted their practice.

“Well-meaning friends and family say to me, ‘Oh, you must be so strong. I could never have handled what you did.’ Rather than a compliment I find this an insult. I want to shout at them ‘NO! I am

not strong – no one is ever strong enough to handle this loss of their child.’ It is not a matter of strength, but one of survival. You either find some way to survive, to put some of the pieces of your life back together, or you don’t. In this process of survival, one may become a stronger person, but at least for me, it certainly wasn’t there to begin with.”

(Bellcross 2012, p. 172)

“Do I feel my patient’s pain more deeply than other genetic counselors? I don’t think so. I simply feel it differently. I believe that all counselors must allow themselves to be vulnerable to some extent. For if we cannot feel with our patients, how can we help them? Every counselor brings to his or her own sessions their lifetime of experiences of joy and pain, sorrow and hope. It is why we do what we do.”

(Bellcross 2012, pp. 173–174)

Both of these experiences profoundly impacted me as a genetic counselor, mostly in positive, but sometimes in challenging ways. As a prenatal counselor at the time of my son’s birth, I wasn’t sure I could return to a position where I was encountering pregnant women, with mostly healthy babies, on a daily basis. Countertransference inevitably occurred, but I tried to be hyperconscious of its presence and learned not to let it interfere with my focus on the patient. It took time, but there is not a doubt in my mind that my personal experiences made me a better genetic counselor. While we all work to be empathic in the presence of our patients’ suffering, there is a depth of empathy that can only come from having lived a related experience. My first-hand knowledge of not only the emotional, but also logistical challenges of having a child with a disability, allowed me to provide valuable guidance and resources for navigating the system. Over time, the realization that I was truly helping these couples from my heart, brought a measure of healing of my own.

“Grief can be defined as the response to loss in all its totality – including its physical, emotional, cognitive, behavioral, and spiritual manifestations – and as a natural and normal reaction to loss. Christopher Hall MAPS, Director, Australian Centre for Grief and Bereavement.”

(Hall 2011, n.d.)

## The Grief Process

Grief is a natural reaction to any type of loss. It is an important adaptive process. When people grieve they are coming to terms with irrevocable change and beginning to find new ways of going about their lives, while coping with the gaps the loss has created. This can take varying periods of time and, as mentioned above, depends on many factors, including characteristics of those who are grieving and of the loss.

Parents of a child with a congenital anomaly or genetic disorder may grieve the loss of the dreams they had envisioned for the child. Individuals diagnosed with an adult onset genetic disorder may grieve the loss of their health and vitality, or the loss of future dreams. For individuals whose loved one has died, the pain of grief can involve missing that person’s presence: sleeping in a bed that’s half empty, craving a scent or an embrace.

## The Original Kübler-Ross Five Stages of Grief Model

The most well-known grief process model is that of Elizabeth Kübler-Ross, author of *On Death and Dying* (Kübler-Ross 1969), in which she proposed five stages of grief (Figure 5.1). Taken consecutively, these stages are as follows:

### Denial

Denial is an important coping mechanism. In relation to grief, it is protective, shielding us from harm. It is the initial paralysis at hearing bad news. Subjectively, denial may feel like a profound numbness or “being in a fog.” Health professionals sometimes mistakenly interpret patients in denial as being uncaring; however, this is rarely the case. Denial allows a patient or parents to “take in” **only** what they are capable of handling mentally, emotionally, and physically. Many in the medical profession try to convince patients of the “facts” of a situation; however, unless immediate action is required on the patient’s part (e.g. parental informed consent for surgery on their child), this approach can be more harmful than helpful. Insisting on acceptance from patients who are not ready can be counterproductive. Patients need time to say goodbye, to let go of one world and move on to another. Denial will pass with time.

### Anger

While anger is a natural part of the grieving process, it can be a difficult emotion for genetic counselors to encounter. In addition to blaming the messenger (which may be you!), patients’ anger during grief can also be aimed at family members, God/Higher Power, the situation, the healthcare system, random bystanders, or even the patient her/himself. It is important for those who are grieving to get in touch with their anger, express it safely, and deal with it. Anger may be processed through journaling, physical activity (such as walks or sports), and/or yelling in a place where no one can hear. It is important for patients to process their anger in a way that does not harm themselves or anyone else – or alienate others with their actions. When many members of a family or group feel a loss, everyone may be grieving at the same time. Emotions may be raw, and words spoken in anger are often not forgotten, with lasting consequences for relationships. Genetic counselors can help by offering couples and families anticipatory guidance in this regard. There will be times during grief when family members need to cool off and when removing oneself from the situation is the best strategy.

Denial	<ul style="list-style-type: none"> <li>• This can't be happening to me.</li> </ul>
Anger	<ul style="list-style-type: none"> <li>• Why is this happening?!</li> <li>• Who is to blame?</li> </ul>
Bargaining	<ul style="list-style-type: none"> <li>• Make this not happen and I will.....</li> </ul>
Depression	<ul style="list-style-type: none"> <li>• I'm too sad to do anything</li> </ul>
Acceptance	<ul style="list-style-type: none"> <li>• This has happened/is going to happen.</li> </ul>

**Figure 5.1** Elizabeth Kübler-Ross' original stages of grief model.

**Bargaining**

Bargaining is an attempt to relieve suffering through striking a deal. People may beg their God/Higher Power to undo the loss, with promises of better behavior or significant life change in exchange for the reversal of the loss. Parents may ask to be taken rather than their children. Bargaining is a last-ditch attempt to try to control life. This phase of grief is often the briefest. It is the final effort on the part of the grieving to hold onto what is important to them. It is an endeavor to find some way to ease the pain of their loss.

**Depression**

Once it becomes clear that anger and bargaining are not going to reverse the loss, many people experience depression. They must confront the inevitability and reality of their loss and their own helplessness to change it. During this period, grieving people may also blame themselves for having caused or in some way contributed to their loss, whether or not this blame is justified. Of note, children, teens, and older adults may react differently to depression. Children may pretend to be sick, worry that a parent is going to die, perform poorly in school, refuse to go to school, and/or exhibit behavioral problems. Older people and people from some cultures may be more willing to discuss the physical manifestations of depression, instead of their emotional difficulties.

**Acceptance**

This stage is about accepting that the loss or new reality is permanent. It is the new norm with which the grieving must learn to live, regardless of how difficult. Their world has been forever changed and readjustment is necessary. Acceptance is a *process* that is experienced, not a final stage with an end point. It is reconciling oneself to a situation that cannot be changed and finding a way to carry on with life. Little by little, families withdraw their energy from the loss and begin to invest it in life. They put loss into perspective, learning how to remember their loved ones and commemorate the loss. If they have a child with a disability, they re-build and re-envision their life plan, to incorporate the adjustments the disability requires.

The process of acceptance may be simply having more good days than bad. As families begin to live again and enjoy their lives, they may feel guilty that in doing so, they are betraying their loved one. Especially after the death of a spouse, older adults with children may find their families have mixed feelings about their tentative efforts to date again, as family members are still dealing with their own grief and reconciliation of loss. External support for all family members may be helpful when grief trajectories clash. What has been lost can never be replaced, but new connections, new meaningful relationships, and new interdependencies can be made. Genetic counselors can encourage families to anticipate and listen to the changing needs of each member as they move forward.

**The Modified Kübler-Ross Seven-Stages Model**

Kübler-Ross (2005) later developed a seven-stage modified model in which she added two additional stages of Shock and Testing (Figure 5.2). In this modified model, shock refers to the initial paralysis at hearing the news of the loss (or impending loss). This stage is a very important one for genetic counselors to understand and appreciate, as it is during this stage that patients experience the effects of the Mental Noise Theory (Covello et al. 2001). Mental noise refers to the phenomenon in which people experiencing

Shock	• Initial paralysis at hearing the bad news
Denial	• Trying to avoid the inevitable
Anger	• Railing at the unfairness of the situation
Bargaining	• Seeking in vain for a way out
Depression	• Feeling too sad to do anything
Testing	• Seeking realistic solutions
Acceptance	• Finally finding a way forward

**Figure 5.2** Modified Kübler-Ross seven-stage model.

high levels of emotional arousal or mental agitation (such as when hearing terminal or otherwise life-changing diagnoses) experience impairment in their immediate ability to hear, understand, remember, or otherwise process information. For this reason, counselors imparting bad news such as a traumatic diagnosis should prepare ahead of time for the possibility that they will have limited time to convey important information, before their patients enter the stage of shock and are unable to process what they are being told. Techniques for dealing with mental noise in genetic counseling are highlighted later in this chapter.

Testing, the second stage added to the Modified Kübler-Ross model, occurs between the Depression and Acceptance stages. In this stage, as patients begin to come out of the Depression stage, they try new ways of interacting with the world, of living within their “new normal.” It is a time of trial and error, when not all new ways tried will be successful; and patients should be encouraged to try many things as they adjust to living without their loved one.

### Criticisms of the Original and Modified Kübler-Ross Models

While helpful as initial models for conceptualizing grief, subsequent research has made clear that the Kübler-Ross stages of grief, in either their original or modified form, do not always follow a linear path (Arizmendi and O'Connor 2015; Boerner et al. 2015; Buglass 2010). Kübler-Ross herself never intended for these stages to be a rigid framework that applies to everyone. In her last book before her death in 2004, she said of the five stages, “They were never meant to help tuck messy emotions into neat packages. They are responses to loss that many people have, but there is not a typical response to loss, as there is no typical loss. Our grieving is as individual as our lives” (Kübler-Ross 2005, as cited in Gettig 2010, p. 102). Thus, although Kübler-Ross’ stages generally characterize part of the grieving process, grief does not always move in a straight line. Stages tend to flow together and fluctuate, and a person may return to the same stage more than once. Emotions are a roller coaster, as overwhelming feelings pass and then return. Moods fluctuate, and just when people think they are “over” it, an anniversary or a sound, smell, or image can send them back into emotional turmoil. This back and forth movement may occur over a period of months, or even years.

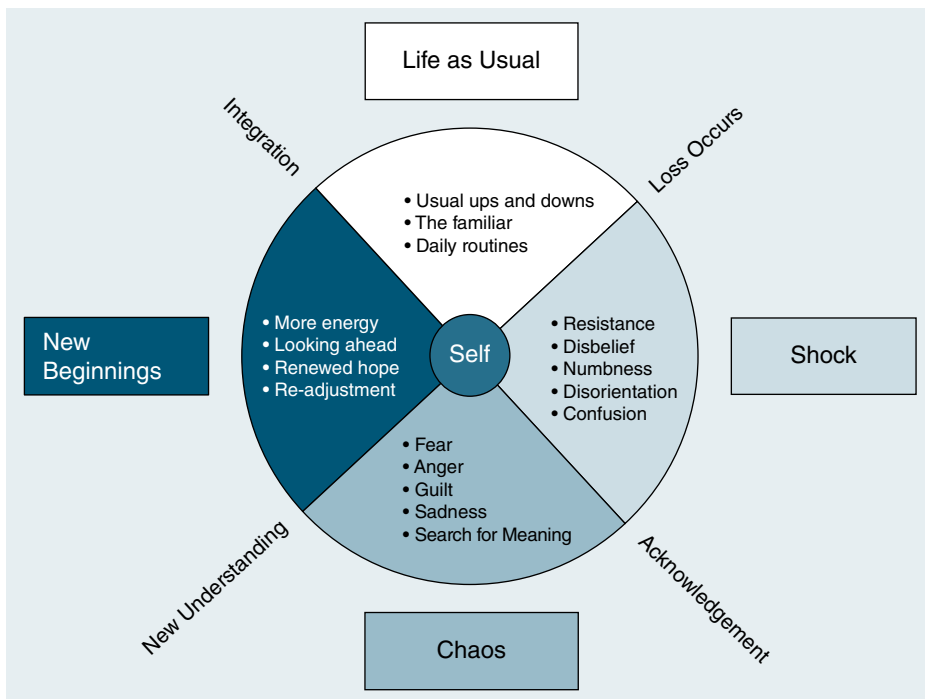
In addition, some authors have challenged the connotations of the word “acceptance.” While not originally intended to convey an embracing of the loss, many lay people have interpreted it that way and may

feel they cannot reach that point. Acceptance is thus sometimes confused with the notion of being alright or okay with what has happened. In reality, this is rarely the case. Many people do not ever feel okay or alright about the loss of a loved one or the birth of a child with disabilities. Subsequent clarifications of the term, stress defining acceptance as the opposite of denial, that is, the bereaved stops fighting the reality that the loss has occurred (implicit in the bargaining stage, for example) and begins to explore the new reality of their life while returning to a healthy level of daily functioning. In recognition of the difficult connotations, some grief theorists have replaced the word “Acceptance” with “Resignation.” The term “Resignation” is not perfect either, misleadingly implying a lack of future happiness. However, it may be more palatable for families living with chronic sorrow (defined later in the chapter), such as sometimes experienced after the birth of a child with a genetic condition limiting the natural lifespan or involving developmental and/or intellectual components.

Taken together with newer models of the Kübler-Ross stages as non-linear, conceptualizations such as that in Figure 5.3 have been suggested.

### Other Grief Models

While the Kübler-Ross’ model and other stage-based models of grief are useful, they are only one way to conceptualize grief. As there have been many more conceptualizations of grief than can be fully examined in this chapter, we limit our description to a few of the more recent ones.



**Figure 5.3** The grieving wheel. *Source:* Hospice Yukon (2019). Reprinted with permission.



### Worden's Task-Based Model

Worden (2008) conceptualizes grieving as consisting of four different sequential tasks: (i) accepting the reality of the loss, (ii) processing the pain of grief, (iii) adjusting to a world without the deceased, and (iv) emotionally relocating the deceased and moving on with life. The first task bears some resemblance to Kübler-Ross' concept of acceptance. Sometimes, those grieving are unable to face the reality of their loss. This can take several forms: (i) denying the facts of the loss (e.g. keeping the deceased's room untouched for years), (ii) denying the significance of the loss (e.g. removing all reminders of the deceased so as not to be reminded of his or her existence), and (iii) denying that death is irreversible. In the latter case, traditional rituals such as burials and cremations may help the grieving accept the loss. Worden asserts that the second task, allowing oneself to feel the pain of grief, is necessary in grief resolution and eventual return to healthy functioning. For some patients, simply giving them permission to grieve will be the most helpful thing the genetic counselor can do.

*A couple whose child had died from Tay-Sachs was seen by a genetic counselor for future family planning. During the session, it became clear the wife was still grieving deeply, while the husband appeared rigid and tense. The genetic counselor asked to speak with the husband individually for a few minutes at the end of the visit and gently asked him about his own coping. He confided that his wife had been so distraught by their son's death that he had felt the need to "stay strong" for her. The genetic counselor shared empathy for him "as a father" and expressed that the child had been his son too, at which point the man broke down sobbing. After several minutes, he composed himself. As he left, he thanked the genetic counselor for acknowledging his loss, too.*

Worden's third task describes the need for the grieving to take on new roles and adjust to changed dynamics in their environment (e.g. the loss of a spouse may require the surviving spouse to learn to cook or balance finances). Genetic counselors can help empower patients in this task by reminding them of their inner strength. In addition, survivors may need to regain their own sense of self, if they have neglected their own needs to care for others preceding or following a death. The final task, emotionally relocating the deceased and moving on with life, requires grievers to form an ongoing relationship with their memories of the deceased. Early in the process, individuals are preoccupied with memories of their loved one. It is as if the psyche has to re-evaluate all aspects of the relationship and get it into perspective, accepting and forgiving the bad and appreciating the good, before letting go. It is not uncommon for the deceased to be remembered as saintly or super-human at this time, but eventually a more balanced view emerges, and the grieving are able to move forward with their life.

### Dual Process Model of Grief

Stroebe and Schut's (1999) Dual Process Model of Grief describes grief as swinging back and forth between two contrasting but equally important coping behaviors (Boerner et al. 2015; Buglass 2010; Hall 2011). The first, "loss-oriented coping," focuses on processing the loss (e.g. dealing with intrusive thoughts about and/or yearning for the deceased). In the second, "restoration-oriented coping," the griever must focus on all of the practical changes brought about by the loss (e.g. arranging the funeral, executing the will and dealing with finances), coping with everyday life, and formation of new roles/relationships resulting from the loss (e.g. assuming the daily roles left vacant by the deceased). This model suggests people experiencing grief are forced to move back and forth between emotional and

practical issues. Alternating between the two behaviors is necessary for adaptive coping, allowing individuals to both experience the emotional depth of their loss and to distract themselves from that depth with the practicalities of life. In the case of a family member with a genetic condition, either in childhood or adulthood, such practicalities can involve juggling work and career demands with increasing caregiver responsibilities, and involve balancing medical appointments and treatments. Genetic examples include lengthy biweekly enzyme replacement therapy infusions for those with Pompe disease, and speech, occupational, and physical therapies for children with Down syndrome.

### **Trajectories of Grief**

Arizmendi and O'Connor (2015) review evidence-based research over the last 20 years dividing the grief process into four different distinct trajectories: resilience, chronic grief, depressed-improved, and chronic depression. Individuals described as resilient show fewer outward signs of distress after a loss, instead displaying a consistently low level or absence of “traditional” signs of grief altogether. Once thought to be maladaptive, the researchers hypothesize this response pattern can sometimes be attributed to positive coping styles and healthy adjustment. The second trajectory is chronic grief, in which individuals continue to experience significant emotional distress and yearning for the deceased which does not resolve (more on this under Complicated Grief). The third trajectory, depressed-improved, describes individuals who experience high levels of clinical distress prior to a loss, followed by an improvement in functioning after the loss (Arizmendi and O'Connor 2015). Research suggests that, while sorrowful, the death of a loved one can also mark the end of a chronic stressor, either for the deceased (if they experienced severe pain or dementia) or the caregiver or both. These individuals experience anticipatory grief before the death of their loved one and mixed feelings of relief and grief after the death. In these circumstances, patients often feel guilty about the relief they feel, and genetic counselors can help significantly by normalizing and validating their feelings.

In the final trajectory, chronic depression, individuals experience high levels of clinical distress prior to the loss, which does *not* improve after the death of their loved one and may even get worse. This trajectory is particularly important for a genetic counselor to be able to distinguish for referral purposes. Patients in the chronic depression trajectory need to be evaluated by a mental health professional for Major Depressive Disorder (if symptoms are related to a history of or ongoing clinical depression) or Persistent Complex Bereavement Disorder (the Diagnostic and Statistical Manual 5th edition's term for significant functional impairment following a loss which does not abate over time) (American Psychiatric Association 2013).

### **Meaning Reconstruction**

Another conceptualization of grief, meaning-making, originally stemmed from trauma theory, which states that trauma disrupts cognitive and emotional processing and processing the trauma is essential to move forward in life (Horowitz 1986). Trauma models see grieving “as a process of reconstructing a world of meaning that has been challenged by loss” (Hall 2011, n.d.). Most commonly associated with Neimeyer (Boerner et al. 2015; Hall 2011; Holland and Neimeyer 2010), the premise is that grief and loss challenge one's sense of self-identity and narrative coherence. Meaning-making, or reorganizing one's life story to restore coherence and maintain continuity between past and future, constitutes the primary task of grief. Most definitions of meaning reconstruction encompass two concepts: (i) making sense of the loss (intellectually, religiously, spiritually, or otherwise relevant to the individual), and (ii) finding

benefits or “silver linings” from the loss (e.g. growth of character, strengthening of other relationships, becoming an advocate for others in similar circumstances) (Davis et al. 1998; Douglas 2014; Hall 2011; Helm 2015). While meaning reconstruction approaches have gained support, they also have their critics. “Difficulties in establishing the role of meaning making in adjustment remain (e.g. studies have not always succeeded in separating the process from the outcome, beliefs from adjustment, or establishing the direction of causality among these factors)” (Boerner et al. 2015, p. 4).

Whichever model of grief you and your patients find most useful, the undeniable similarity is that there is no timetable for grieving. While the sense of loss and the intermittent sadness may never go away completely, people experience the process of grief differently. Some find that within a few weeks or months the period between waves of distress lengthens, and they are increasingly able to feel peace, renewed hope, and enjoy life. Others may face years of being hit with what feels like relentless waves of grief. Although varying from person to person, it is not unusual for the active portion of grieving to last 1–2 full years or more. Understanding the process of grief using whatever model resonates most with the individual patient can help patients see they are not alone in their confusion, turmoil, and pain, and that life can improve.

## Types of Grief

In this section, we describe some of the most common types of grief in more detail. As genetic counselors, it is particularly important to become familiar with these types, as the world of genetics often lends itself to unusual or special circumstances. We discuss later in the chapter how to distinguish when patients need additional assistance and when a referral to mental health professionals is appropriate.

In the past, the term “classic grief” was used to denote grief following the death of a loved one. Classic grief occurs without unusual circumstance, and progresses without incident to allow the grieving individual to return to normal daily functioning. While this is certainly one kind of grief, it is not the only type, and it is important that it not be confused with or described to patients as “normal grief,” as this implies all other types of grief are pathological. The man who is grieving the loss of the woman he once knew, as he takes care of the woman she has become, in advanced cases of Alzheimer’s disease is not experiencing pathological grief; he is experiencing both anticipatory grief and ambiguous loss.

### Anticipatory Grief

Anticipatory grief refers to grief that occurs prior to a loss, as opposed to during or after a loss (Hamilton 2016). In addition to grieving the eventual loss of their life, patients may grieve their upcoming loss of mental and/or physical functionality, loss of independence, loss of control, loss of dignity, loss of identity or role (e.g. breadwinner or caretaker in the family), loss of future and/or loss of lifestyle. Family members may likewise anticipatorily grieve the loss of relationship, loss of security, and/or loss of lifestyle. Anticipatory grief is common among patients and family members of patients who receive terminal or otherwise life-altering diagnoses, such as amyotrophic lateral sclerosis (ALS), late-onset Pompe disease, and end-stage cancer. Nowadays, in the relatively new world of predictive testing, an individual or family may go through anticipatory grief years and even decades before symptoms begin, for example, upon confirmation of the presence of the Huntington mutation in one’s early 20s. One benefit of anticipatory

grief is that it may allow for differences in life planning, such as career and/or family decisions, as well as preparation for the loss, including a chance to “take care of unfinished business.” Even some of the practical issues surrounding death (e.g. financial planning, funeral arrangements) may be done ahead of time and, in some cases, the person whose death is anticipated may have the chance to make their wishes known or even take care of such matters themselves (Boerner et al. 2015).

In a qualitative study involving parents of children with Spinal Muscular Atrophy Type I (SMA 1), Higgs et al. (2016) observed several reoccurring themes, including that of anticipatory grief. Other themes included feeling like it was their (the parents’) fault, feeling helpless to change the situation, and experiencing multiple associated losses, including reproductive freedom:

“Not only did [SMA] affect my child and it took my child’s life, but it’s the whole thing of your next child ... the simplest thing that a human can do [conceiving a child naturally] is not simple anymore.”  
(Higgs et al. 2016, p. 43)

### Ambiguous Loss

Ambiguous loss occurs when there is a discrepancy between the mental and physical presence of a loved one. Boss (1999) defined the two types of ambiguous loss as:

*Type One* – when a loved one is physically absent, yet their psychological presence remains. These include situations in which a loved one is physically missing or bodily gone, yet there is no definitive proof of death. Common examples include situations of absent parents due to divorce, placing a baby for adoption, and loss of physical contact with parents and siblings due to immigration. Catastrophic examples include kidnapping and missing bodies in the context of war, terrorism, ethnic cleansing, genocide, and natural disasters such as earthquake, flood, and tsunami.

*Type Two* – when a loved one is physically present, yet absent psychologically. This includes situations in which the loved one is emotionally or cognitively missing. Such ambiguous loss can occur with Alzheimer’s disease and other dementias; traumatic brain injury; AIDS, addiction, or other chronic mental or physical illnesses that take away a loved one’s mind or memory. While their physical body is present, the person they once were is gone.

### Disenfranchised Grief

Disenfranchised grief occurs when a loss cannot be openly acknowledged, or may not be socially sanctioned (Doka 2002). Individuals experience this type of grief in the context of societal norms that attempt to dictate who, when, where, how long, and for whom people should grieve (Hall 2011). Disenfranchised grief can happen in deaths involving social stigmas (e.g. HIV/AIDS or extramarital affairs). It can also happen in cases of miscarriage, pregnancy termination, and genetic conditions – particularly those associated with significant physical or intellectual disabilities.

Todd (2007) describes how the death of children with intellectual disabilities may be associated with a type of disenfranchised grief, which he calls “silenced grief.” Such deaths can sometimes be viewed by society as a lightening of burden. Acquaintances and even extended family members may suggest that the parent’s life “can go back to normal now” or even that “it must be a relief,” rather than acknowledging the

child's death as a true loss and offering support for the genuine grief the parents are feeling. Some parents may experience a sense of relief mingled with their devastating loss, leading to feelings of guilt (Todd 2007). Guilt may also arise if the parents at times felt their life so painful and overwhelming that they momentarily hoped their child would die – especially before they themselves do. Such feelings often stem from their worry about who will watch over their child after their own death. The death of a child with disabilities is often compounded by the loss of identity and purpose, especially if the parents' lives completely revolved around caring for their child. They may also lose their system of social support, friends and connections made through their child's disability, with whom they may have developed deep bonds. In this sense, they no longer “belong to the club” and may struggle to adapt to what others consider a “normal life” (Todd 2007). Even the world of disability services, containing individuals parents may have known for years, may disappear as parents no longer “qualify” to receive them. In some circumstances, parents themselves may no longer wish to associate with these individuals and families, as such interactions represent constant reminders of what they lost and/or exacerbate feelings of guilt the parents may be experiencing over the relief that their struggle and their child's struggle are over. Strong connections with faith communities and employment, even part time, outside the home can be buffers for such compound loss, as these environments comprise a social network independent of their child's disability (Todd 2007).

### Complicated Grief

Both ambiguous loss (especially in catastrophic cases of type 1) and disenfranchised grief can increase the risk of complicated grief. This term is used when adaptation to one's new reality is impeded; that is, when grief involves functional impairment which either does not abate, or resurfaces over time. Other risk factors include traumatic or violent deaths, multiple deaths, concurrent stressors (e.g. divorce, bankruptcy), history of mental illness or substance abuse, and lack of support systems (Arizmendi and O'Connor 2015; Hall 2011; Shear et al. 2017). Complicated grief reactions occur in an estimated 10–15% of cases (Hall 2011; Mancini et al. 2012). They may include any of the grief process experiences described previously; however, reactions may be intensified, prolonged, and interfere with the griever's psychological, social, and physiological functioning. While some clinicians worry about medicalization or pathologizing of grief, research shows being able to appropriately distinguish cases of complicated grief helps clinicians identify when individuals may benefit from additional support (i.e. referral to mental health or other support services), and results in fewer prescriptions for anti-depressant medications (Lichtenthal et al. 2018). As such, it is important for us as genetic counselors to be able to distinguish cases of complicated grief and offer referrals and resources to our patients as needed. A few of the more common forms of complicated grief are described next:

- *Exaggerated Grief* – grief in which the individual's initial functional impairment becomes worse over time rather than better. In such cases, individuals may resort to self-destructive behaviors, and professionals should monitor the potential for suicidal ideation.
- *Masked Grief* – grief in which the individual is not aware that behaviors interfering with normal functioning stem from their loss. Submersion in work to the exclusion of emotional accessibility to loved ones may occur with both masked grief and the next type, delayed grief.
- *Delayed Grief* – when an individual consciously or unconsciously suppresses or postpones their grief, displaying a small or nonexistent reaction at the time of loss. In such cases, a later smaller incident may trigger a disproportionate reaction, resurrecting unresolved grief from the first loss.

*A mother whose son had Hurler syndrome seemed to cope well with his diagnosis and threw herself into organizing a support group and raising money for research. Her son had a relatively mild course and it was not until she met a family whose child, the same age and gender as her own, had a milder form of Hurler, that her coping collapsed. She had believed her son was the least affected child with this diagnosis. Being able to minimize her son's condition allowed her to cope. Once she met a child less affected, the mother required psychiatric hospitalization because she could not deal with her son's diagnosis.*

- **Chronic Grief** – when an individual's intense grief reactions do not subside and continue over very long periods of time. Studies show that for most people, grief intensity lessens after a period of approximately six months (Hall 2011). This does not imply that grief is absent, but rather that it no longer results in functional impairment. When the intensity of grief does not abate and individuals are not able to resume functioning, chronic grief may be the appropriate characterization.

Wellisch and Cohen (2010) found that women with hereditary risk for breast cancer, whose mother died of the disease, were at increased risk for chronic grief. They observed that patients at UCLA's high-risk clinic often had grief reactions which did not resolve by 12–14 months and suggested the grief may potentially linger for the daughter's entire life. While depression diminished, self-rated grief scores remained in moderate–high categories. Wellisch and Cohen (2010) concluded that these patients may experience not only complicated grief, but symptoms of Post-Traumatic Stress Disorder (PTSD): “The actual death of a mother from breast cancer creates the separation anxiety typically related to complicated grief, whereas the risk of breast cancer to the daughter creates avoidance and experiences of distress typically related to PTSD” (p. 12). To address this dual challenge, they suggested emphasizing that “biology is not destiny.” In this context, genetic counselors can empower these women to rewrite their own narrative by focusing on how knowledge of their mutation status provides access to preventive measures and enhanced screening, to increase women's confidence that “what happened to my mother won't necessarily happen to me.”

## Chronic Sorrow

It is critical to distinguish chronic grief from chronic sorrow, which is particularly relevant to families of individuals with genetic conditions. Chronic sorrow refers to the concept that parents of children with chronic illness and/or developmental and intellectual disabilities may experience lingering feelings of sadness and grief throughout the life of their child. They experience the same psychological, social, and physiological functional impairment as anyone else in the initial throes of their grief reaction to their child's diagnosis. However, in contrast to chronic grief, functional impairment does not persist. Parents are usually able to adapt in time to their new reality, re-building, and re-envisioning their life plan to incorporate the adjustments their child's illness or disability requires. It should be noted however, that regardless of how much they love their child, the layperson's concept of reaching “acceptance” may not resonate with them. Instead, as Douglas (2014) states, “their happiness may co-exist with chronic sorrow” (p. 697).

Coughlin and Sethares (2017) provide a comprehensive look at the literature surrounding the concept of chronic sorrow. A mother may re-mourn the loss of the child she expected to have when her friends experience “empty nest syndrome,” while her son with developmental disabilities will never be capable of living on his own. Such grief is not pathological, but instead a reflection of chronic sorrow. Factors found to affect parental experiences of chronic sorrow include witnessing discrepancies between their

child's developmental and life milestones and those of siblings and/or other children, the degree to which health-related medical interventions were required, and internal triggers such as fear of the future or anticipating their child's death. They may also experience uncertainty and guilt regarding time taken from their other children, and face challenges associated with necessary lifestyle changes including financial, school/daycare issues, and social interactions.

“The struggle of course has not ended. For this is truly a chronic unending sorrow. Not a day goes by when I do not wish for the little boy that should have been. For me acceptance will always be a process. I cannot conceive of ever fully accepting what happened to my son. For to me acceptance implies that I am embracing this reality as having a meaning or purpose. I feel strongly that there can be no purpose to the suffering of innocence. It is simply an inescapable part of human existence, and it strikes at random, without cause.”

(Bellcross 2012, p. 171)

The genetic counselor should also be aware that mothers' and fathers' experiences of chronic sorrow may differ (Coughlin and Sethares 2017). Research has shown that mothers tend to experience more intense grief reactions, feelings of guilt, and fear for the child's future. Depression is also more common in mothers, while fathers more often experience a sense of confusion. While fathers seem to adjust in a gradual, time-limited manner, mothers experience more highs and lows and periodic crises. Mothers tend to share feelings readily, while fathers find it more difficult to express their grief and sorrow. The majority of studies indicate that while fathers tend to resolve their grief, chronic sorrow may be ongoing for mothers (Coughlin and Sethares 2017). Finally, the experience of chronic sorrow may be compounded by a potential loss of spousal support and dissatisfaction with the marital relationship or divorce (Risdal and Singer 2004). However, while it is well-recognized that having a child with disabilities increases parental stress, more recent studies have found no difference in divorce rates compared to parents of typically developing children (Hartley et al. 2011; Namkung et al. 2015). In some cases, the parental bond may even grow stronger – “There have been times when it has been a real strain on the marriage. But overall, I think it's made me a better person. And it has made my husband and I a stronger couple' (mother of an adult son with Fragile X syndrome)” (Hartley et al. 2011, p. 2).

## Perinatal Grief

The unique yet ubiquitous circumstances of perinatal grief have earned a separate section in this chapter for two reasons – (i) they are often unacknowledged by the rest of society, especially in cases in which expecting parents have not yet shared with anyone the news that they were expecting a child, and/or have made the decision to quietly terminate their pregnancies, and (ii) it is a type of grief which genetic counselors may encounter with frequency, especially those who work in prenatal settings. Perinatal loss includes miscarriages, fetal death >20 weeks (stillbirths), pregnancy terminations and neonatal death. Each may be associated with differential parental experiences of grief, though their experiences share some common features.

While grief following miscarriage is common, the experience may vary widely, with some individuals experiencing little to no grief, and others, perhaps as high as 25–30%, suffering from prolonged or complicated grief reactions (Kersting and Wagner 2012; Kong et al. 2013). Both mothers and fathers experience



grief reactions in response to a miscarriage, and while it typically resolves by four to six months, it is often more intense and may be prolonged for the woman (Volgsten et al. 2018). Factors affecting the intensity of the grief reaction include whether the couple have had a previous child, a prior miscarriage, or experienced infertility (Robinson 2014; Volgsten et al. 2018). Complicated grief following perinatal loss is primarily predicted by two factors: poor social support, and a history of a mental health condition such as major depression (Kersting and Wagner 2012).

A challenge to the resolution of grief after miscarriage is that “It’s just one of those things people don’t seem to talk about...” (Bellhouse et al. 2018, p. 1). The silence around miscarriage in part stems from a trend not to disclose the pregnancy early on, as well as the woman’s discomfort discussing the event. Both limit the opportunity for support and may increase feelings of isolation. Box 5.1 provides suggestions Bellhouse et al. (2018) gathered from women experiencing miscarriage that may be helpful in reducing the stigma and breaking the “silence.” There are multiple resources for women/couples experiencing miscarriage. One that I (CB) used frequently as a prenatal genetic counselor is *Miscarriage, A Shattered Dream* (Ilse and Hammer Burns 2002).

In contrast to miscarriage, stillbirth is typically not “silent.” The prenatal attachment is often stronger, as friends and family are anticipating the birth. The loss may feel more “real,” akin to a neonatal death or infant loss, as there is tangible evidence that a baby existed. In stillbirth situations, legitimization of the loss remains critical – the couple may feel they are parents, but there is no child. Does this mean their baby was “less than a person”? (Burden et al. 2016). These parents may struggle with how to respond when strangers or acquaintances innocently ask if they have children. Fathers in particular, may feel marginalized. Differing grief reactions can lead to relationship conflict, and separation is frequently reported in both cases of miscarriage and stillbirth, though the effect appears to be longer term in the latter circumstance (Gold et al. 2010; Robinson 2014). In addition, there may be more profound effects on other immediate family, including siblings and grandparents, who were also expecting the baby. Stillbirth can negatively impact the woman’s body image, as the physical signs of a pregnancy exist, but there is no baby to show for it. Both miscarriage and stillbirth are often associated with guilt reactions on the part of the mother, the sense that somehow her body failed both her and her child. Congenital anomalies or a genetic cause may intensify these feelings.

Prenatal diagnosis of a fetal abnormality can be a particularly difficult perinatal grief experience. While parents react with many of the emotions seen after the death of a loved one, there is the added

#### Box 5.1

- Tell friends and family that you are pregnant in the first trimester, so that if a loss occurs, support is available. (*Authors’ note: some couples may prefer to wait until any early prenatal testing comes back normal, so as to avoid societal and familial judgment if they decide to terminate.*)
- Being open about miscarriage on a social network level, increasing awareness of miscarriage as a loss.
- Friends and family can provide support by acknowledging the loss for what it is, and not diminishing its importance by saying “it’s common” or “you’ll get pregnant again.”
- Legitimize the loss by providing practical support such as meals, childcare, etc. as one would with any other loss.



component of guilt, and the burden for some parents of being faced with an “impossible choice.” Authors have described the experience of a prenatal diagnosis of fetal abnormality as a “trauma experience” (Statham et al. 2000). Parents coping with this loss, and wrestling with decisions, particularly in the current era of prenatal screening and testing, are often forced to deal with ambiguity regarding prognosis. An article examining parental reactions to abnormal or uncertain microarray results, as an optional addition to invasive testing, described the concept of “toxic knowledge” (Bernhardt et al. 2013). It has been noted that termination of pregnancy for fetal abnormality can result in greater psychological trauma than abortion for other reasons (Hodgson and McClaren 2018). Indeed, grief and distress under these circumstances may also be comparable to PTSD, as it is complicated by the parents’ choice to end the pregnancy. In addition, the parents may face judgment from friends, family, or society and not have access to their established support networks.

As a prenatal counselor, I (CB) found the resource *A Time to Decide, A Time to Heal* (Minnick and Delp 2000) of particular assistance to patients in these circumstances. As a genetic counseling program director, I feel this booklet should be required reading. Though I had not personally been faced with this decision, I learned so much from reading the parents’ heartfelt quotes and seeking an understanding of what they experienced. One quote from this booklet particularly resonated with me: “The rest of the world will never know how very hard it was to make that decision. They won’t realize how desperately you searched for all the answers to help you decide. And there will always be a very small piece of your heart that will wonder about the decision” (p. 9).

Inspired in part by this booklet, I initiated a support group for parents who had terminated a pregnancy due to fetal abnormality. The love of these mothers for their never born children was beyond what I have felt in many mothers receiving a normal prenatal diagnostic result. We may, as individuals, have our own perspectives on choice. The profession we have chosen, however, demands we not only respect parents’ decisions in this regard, but also support them in the process and acknowledge their decision comes not from selfishness, but love, and may be associated with intense and sometimes complicated grief reactions.

In this situation, the process by which the parent(s) make the decision can profoundly impact their grief response. There will be grief associated with either continuing or ending the pregnancy – as both outcomes result in the loss of the hoped-for child. While many individuals may state they know the decision they would make up front, it can still become a significant struggle. Parents may find themselves making a decision that is opposite of what they had anticipated, so we should never make assumptions. What is critical is that we as genetic counselors openly provide both options, with information and support to facilitate the decision-making process. Normalizing the parents’ choice, reassuring them that others have made similar decisions, and acknowledging that the choice they make will be right for them, can alleviate some of the feelings of uncertainty and guilt that accompany abnormal prenatal diagnosis.

With all forms of perinatal loss, encouraging parents to engage in some form of “memory-making” may be beneficial. This can be as simple as planting a new tree in one’s yard, releasing some balloons on a hilltop, holding a private funeral service, or a small keepsake or symbolic memento of their lost child. While it used to be the norm for women experiencing stillbirth to have the child whisked away, it is now the standard of care for healthcare providers to encourage parents to see and hold the baby as part of the mourning and grief resolution process. However, some data have shown that doing so may result in increased rates of depression, anxiety, and PTSD (Hughes et al. 2002; Turton et al. 2009). Knowing this, caregivers should not pressure the mother or father into seeing and holding the infant. Parents must be

allowed to individually choose this option, as for some it may be healing and for others traumatic (Robinson 2014). If other family members are present (e.g. grandparents), they too, should be given this opportunity.

Applying predictive measures of grief intensity to identify patients who need follow-up may be beneficial. The Perinatal Grief Intensity Scale (PGIS) has demonstrated validity and reliability in identifying women who may experience future intense or complicated grief surrounding perinatal loss, and it has a lower response burden than previous measures (Hutti et al. 2017).

## General Strategies for Addressing Grief

Working with grieving patients begins with acknowledging their loss. Recovery from loss begins with validation of the loss itself, while invalidation increases the risk for disenfranchised grief. Western society often avoids talking about death, to the extent that friends and acquaintances may refrain from mentioning the name of the deceased so as not to remind those grieving of their loss. On the contrary, those grieving have not forgotten their loss and may need to talk occasionally, to hear the name of their loved one and remember them aloud, or simply to process what they are feeling at that moment in time. In this vein, it is important that we do not shy away from our patients' grief. Addressing our patients' grief can be challenging, especially for young counselors who may not have gone through an intense grief experience themselves. We may feel awkward and tongue-tied in response to patients' grief reactions, be it anger, denial, or flowing tears. This is of course, where *empathy is critical*. Using silence, non-verbal cues, and simply acknowledging patients' grief is often more critical than "saying the right thing."

*Normalization is also an important tool.* If a patient has never before experienced a traumatic loss, they may be unprepared for the intensity of the acute grief experience and/or their inability to think and function normally (Shear et al. 2017). Normalizing their experience and reassuring them that this phase of emotional intensity and disruption will not last forever can be reassuring to patients who fear that it will. Likewise, normalization of the anger that can be experienced toward a higher power during acute grief can be helpful for religious patients who may believe such anger is not permissible (for such patients, genetic counselors should also recommend they talk to their priest, minister, imam, rabbi, etc.).

*Providing anticipatory guidance is also helpful.* Even when patients are too distraught to fully process information (e.g. mental noise and/or aspects of denial), anticipatory guidance is a vital part of any genetic counseling session. Including your anticipatory guidance in your written summary for patients to take home will help to offset the effects of mental noise. Such guidance may include elements of some of the grief theories discussed earlier. For example, letting patients know that at times they may feel angry, or that it is normal to re-experience grief in response to various "triggers" (e.g. the anniversary of a loss, or when other parents' children reach a milestone that your child may never reach). Anticipatory guidance may also include cautioning partners that they may experience their grief differently, so as to normalize and help them understand each other's potentially contrasting needs and reactions. Appendix 5.A contains additional examples of anticipatory guidance.

In some cases, it may also be necessary to give patients "permission" to grieve, especially when they are feeling societal pressure to "remain strong" or stifle their grief (e.g. stereotypical masculinity roles, cultural expectations, cases of disenfranchised grief). Reminding patients that not everyone experiences grief at the same pace and giving them permission to continue grieving may be particularly helpful for patients whose employers and coworkers expect them to be back on the job within two weeks and functioning as before.

Just as importantly, it may be necessary to give patients permission to laugh at times, as many may feel guilty at doing so after the death of a loved one. Reassure patients that just as it is important to allow one's self to grieve, it is also okay to take a break from grief.

When you are in session with a patient who has experienced a loss, don't be afraid to ask about their loved one (whether the loved one has died or is living with a genetic condition). While some patients will prefer to grieve alone or in the privacy of their family, others will find comfort in talking about their grief with you. Allow the patient to share stories of their loved one, if they wish. You needn't say much during this portion of the session, instead offering empathic listening and bearing witness to their grief, without any attempt to "fix" it. Even brief interactions may be helpful in reducing a patient's sense of isolation.

Another reason not to shy away from discussion of our patients' losses is the need to assess how they are coping and whether they may need additional supportive resources or referrals. Ask your patient how s/he is coping on a daily basis. Explore the range of feelings and challenges they are experiencing and how the loss is affecting their daily activities, social interactions, and their work (Shear et al. 2017). Ask about and explore their existing support system and its effectiveness. If they appear to have few avenues of support, provide local or online resources (e.g. support or advocacy groups, contact information for families who have experienced the same type of loss or condition and have given permission for their contact information to be shared). Signs that a grieving patient is beginning to adapt to their new circumstances include a gradual return to daily functioning, emotional stability, joy and enthusiasm for life, and re-involvement in established relationships (Shear et al. 2017). While adaptation is rarely the end of grief, failure to adapt over time should be a sign for the genetic counselor to consider referral to more specialized grief and/or mental health professionals.

Distinguishing when such referrals are appropriate is an important part of a genetic counselor's job. Patients with a pre-existing history of depression, anxiety, or other mental illness, and/or a history of substance abuse may be more likely to struggle in adapting to grief (Arizmendi and O'Connor 2015). Adaptation difficulties may also occur when the circumstances surrounding a loved one's death are especially violent, and/or in cases involving the death of a child. Such factors increase the chance that grief may trigger clinical episodes of major depression, anxiety disorders, mania, and/or PTSD, as well as substance abuse and risk-taking behaviors (Hall 2011; Shear et al. 2017). In such cases, it is critical that the genetic counselor check for suicidal ideation and make appropriate referrals. While depression is a natural part of the grieving process, it is important to distinguish between grief-associated depression and clinical depression (Shear et al. 2017). Both can involve intense sadness, hopelessness, sleep disturbances, difficulty concentrating, changes in diet, loss of interest or pleasure in daily activities, and a wide variety of physical complaints, such as gastrointestinal problems, headache, and backache. However, there are also important differences between the two, described in Table 5.1.

### Addressing Grief in the Context of Genetic Counseling

Despite the strong association of our profession with exposure to patient grief experiences, there is relatively little in the literature regarding grief specifically in the context of genetic counseling. Strategies found to be most helpful to parents of a child with a newly diagnosed genetic condition include providing information, compassionate care and resources (Coughlin and Sethares 2017). Parents need accurate information regarding the child's condition and treatment, but they also benefit from being given hope. Education regarding resources for children with disabilities can assist in this regard. Compassionate care

**Table 5.1** Comparison of grief and major depression.

Grief	Major depression
Intense yearning or longing for missing loved one or previous reality	Uninterrupted feeling of apathy
May come in waves and is experienced most severely when focusing on the loss	Is more likely to be static
Closeness of others may provide comfort (though can include intermittent withdrawal and isolative behaviors)	Persistent withdrawal and isolative behaviors
Fluctuating ability to feel pleasure	Persistent flat affect and/or compromised capability for positive emotion
Able to feel a wide range of emotions	Fixed emotion, feeling “stuck”
Preserved feelings of self-image and self-worth	Feelings of worthlessness and self-loathing
Often responsive to societal offers of support	Frequently unresponsive to support

includes acknowledging and normalizing parental feelings – encouraging them to be strong, but allowing them to be weak, and recognizing their efforts while empowering them. Finally, ensuring access to respite, community resources and support is critical (Coughlin and Sethares 2017).

Drawn in part from other resources on grief, Douglas (2014) provides several useful concepts and illustrative phrases that may help genetic counselors assist their patients in adjusting to having a child with a disability. Table 5.2 contains a compilation of these concepts and phrases. While the clinical scenario is the birth of a child with Down syndrome, the concepts apply to many patient experiences of genetic loss. A focus of Douglas’s article is assisting the patient with the process of “meaning-making,” (mentioned earlier) when assisting patients in coping and adjusting to their grief and loss. However, she specifically cautions that while “providing hope” is an important concept, timing is critical, so as not to inadvertently lead the patient to suppress feelings of grief.

Helm (2015) further explored genetic counselor use of “meaning-making strategies” to help parents adapt to receiving a rare diagnosis. He and others caution, however, against the use of such strategies too soon after the event, when patients may be in a state of acute grief (Douglas 2014; Helm 2015; Shear et al. 2011). Helm’s approach is to support and empower parents of children with rare genetic conditions. “I frame the diagnosis [of Mowat-Wilson] as not one of isolation and hopelessness, but of empowerment – she [mother] will become an expert on MWS and be in the position to help other families with experiences of MWS” (Helm 2015, p. 207). Helm recommends suggesting to parents that they become involved in support groups, participate in registries and research studies, and create blogs or web-pages as a means of empowerment. By encouraging parents to become advocates and experts and facilitating connections, the genetic counselor can more actively facilitate their journey through the grief experience (Helm 2015).

*The mother of a little boy with Krabbe disease was very realistic about her son’s prognosis and devoted herself to his care during his life. Holding her baby in her arms as she was given his diagnosis, she asked, “So I guess we don’t need to worry about sleep-training him then?,” to which his doctors answered, “No, just hold him and love him as much as you want.” After her son’s death, this mother*

**Table 5.2** Concepts and phrases helpful for pediatric genetic sessions.

Concept	Example Phrases
Normalize ambivalent feelings	“It’s natural to feel that way” “Many parents in the same situation express the same feelings”
Name and validate the loss	“You have experienced a loss here. You were picturing a typical child [like your daughter] and what you received is not what you were expecting. It’s okay to feel disappointed and upset by this.”
Ask specifically how the patient is doing	“It sounds like it’s been a difficult few months for you. How do you think you’re coping with the surprise of this diagnosis? What has been the hardest thing for you?”
Explore spiritual and/or existential beliefs of the patient	“Some people have told me that ‘everything happens for a reason’ or that ‘God knows best’. How do you feel about that? Are you religious? Do you believe in a higher power? How might what has happened fit with your religious beliefs?”
Compliment the parents’ strengths and resiliency	“Well, it’s been a year since [son] was born. Congratulations on getting through the year. You are always consistent with confirming your appointments with us and following through even though it might not be easy to make all of the appointments. I’ve been impressed by that.”
Ask the patient to reflect back on their story (ex – after a year)	“Would you tell me the story of the pregnancy, the birth of your son, and when you found out he has Down syndrome? How did you make sense of what was happening? How have things changed since your son was born? What roles have you gained? What roles have you lost? Has your view of life changed? In what ways? What strengths have you seen in yourself?”

Source: Adapted from Douglas (2014), p. 698.

*threw herself into advocacy for Krabbe, including legislation for the addition of Krabbe to newborn screening and working with Hunter’s Hope. Recognizing this mother’s need to give her son’s death meaning, her genetic counselor helped her get in touch with professors at a local medical school, where she began speaking to classes of medical students and genetic counselors as well.*

While this road to meaning-making is very successful for some families, not all parents will want or be able to find it within themselves to become experts and advocates. How do we empower these parents and help them make meaning out of their situation? Empowerment can come in the form of acknowledging they are “heroes” simply by loving and caring and doing everything they already are for their child. We need to be conscious of recommending activities that if not met, may make the parents feel they are not doing enough.

Multiple resources exist to assist parents experiencing genetic loss. A famous poem, often shared with parents of a child with disabilities, is “Welcome to Holland” by Emily Pearl Kingsley (1987). Well worth reading, it describes how having a child with a disability is like planning a trip to Italy, only to find oneself in Holland. Holland is not Italy, it is not what you planned, but it has windmills and tulips and Rembrandts. “... if you spend your life mourning the fact that you didn’t get to go to Italy, you will never be free to enjoy the very special, the very lovely things about Holland” (cited in Gettig 2010, p. 117). While this poem resonates with many, not all parents will find comfort in its words, especially early in

the grief process (Craver 2015; Fields 2016). I (CB) fell into this category. It is not to say there isn't joy and beauty in raising a child with a disability, but sometimes it can be difficult not to see the broken slats on the windmills, or the tulips that are fading. Is Holland just as good as Italy? Obviously, the answer to this is in the eye of the beholder. To me, "Italy" and "Holland" are not directly comparable. In considering the resources we offer our patients experiencing the grief process, it is important to first explore where the patient is internally and what they are feeling at that moment, before suggesting a particular resource at a particular time.

### Genetics Professionals' Reactions to Grief

Relatively little has been written about how genetic counselors react to the grief their patients experience. A survey of 300 genetic professionals found that the majority (80%) reported feeling comfortable in the presence of grief and loss (Geller et al. 2010). In addition, less than 30% felt they had been inadequately trained to deal with these issues. However, there were significantly higher levels of distress among those who felt uncomfortable and unprepared, suggesting the need for targeted training and support (Geller et al. 2010). Factors associated with feelings of discomfort included perceived adequacy of training, comfort with uncertainty, personal loss experiences, and the meaning derived from patient care (Geller et al. 2010).

Working in a profession where one encounters grief on perhaps an almost daily basis, can of course take its toll. The experience of witnessing others' grief touches us personally. It may remind us of our own past losses or make us aware of the losses that we fear, opening the door to countertransference (discussed in Chapter 8). For this reason, it is important for genetic counselors to reflect upon and explore their own history of loss. Appendix 5.B contains examples of ways to do this. Counselors must also continually evaluate their own reactions, and be aware of signs of potential burnout or compassion fatigue. These concepts, as well as strategies for dealing with them, are covered thoroughly in Chapter 15.

### Cultural Considerations

Grieving and death rituals vary widely across cultures and are often heavily influenced by religion. Cultures have different mourning ceremonies, traditions, and behaviors to express grief. These include the degree of openness in discussing family history and health problems in a medical setting, the way in which different types of mental and physical disabilities are viewed in terms of their impact on individuals and families, and barriers to receiving services such as language and health care beliefs at variance with Western medicine. In order to provide appropriate and useful services, genetic counselors must thus have information and experience regarding the beliefs and practices of the ethnocultural groups they serve. Equally important, however, is sensitivity to cross-cultural interactions, achieved in part through thoughtful exploration of one's own ethnocultural identity and heritage.

"The first Hindu family I worked with undergoing a pregnancy termination taught me a number of lessons. I was not familiar with Hindu traditions so discussed with the family the usual options we offered couples such as viewing the baby after delivery, providing photos or footprints, offering them the clothing of the baby, etc. They advised me what was consistent with their traditions and most helpful of all provided me a contact with their temple. The priest assisted the family and me.

The couple visited our center for a follow up visit and said that part of their religious tradition was cremation, which had been performed at their request, and they wanted to obtain ash from the cremation so a ceremony could be performed in memory of the baby at the temple.

Unfortunately, at the gestational age of the pregnancy, little, or no ash is available and with the passage of time what remains might have been available were now gone. I called the priest and we discussed the situation. He asked if any item from the pregnancy or baby still existed. I said, “Well, the lab still has slides from the testing.” Together we concluded that grinding the slides in a mortar and pestle would create ash from the baby and this material could be [and was] used in the ceremony for the baby.”

Excerpt from Gettig (2010, p. 118)

In some cultures, and social contexts, outward expression of grief may be encouraged, while in others a subtle message may be given that the individual should stop grieving and get on with life. For example, mourning of a stillbirth (or neonatal death) is often not considered acceptable in some cultures, complicating the healing process (Burden et al. 2016). In these circumstances, societal expression of grief may be considered unhealthy and demoralizing, with the proper action of a friend being to distract the mourner from grief. However, such responses may significantly impair the parental healing process (Stroebe and Schut 1999; Worden 2008).

Cultural sensitivity is addressed in detail in Chapters 10 and 11. In terms of grief, just keep in mind that every ethnic group and religion has its own grief traditions. If the counselor is unsure what to do, ask the family or their traditions expert – a rabbi, imam, priest, minister, elder family member, anyone who knows what to do. Box 5.2 contains examples of questions to ask patients.

### Box 5.2 Questions to Reveal Cultural Responses to Grief

- What are the cultural rituals for coping with dying, the deceased person's body, the final arrangements for the body, and honoring the death?
- What are the family's beliefs about what happens after death?
- What does the family regard as a normal expression of grief and the acceptance of the loss?
- What does the family consider to be the roles of each family member in handling the death?
- Are certain types of death less acceptable (for example, suicide), or are certain types of death especially hard to handle for that culture (for example, the death of a child)?

## Conclusion

Like everyone, we will experience grief in our own lives, but being genetic counselors means we will inevitably encounter grief through our interactions with patients and families as well. Understanding the different types of grief, the grief process, and situations unique to genetic-related grief is essential to providing care for our patients. It allows us to provide the empathy necessary to help our patients successfully navigate their grief journey. Reflecting on our own grief experiences enhances our ability to comprehend grief reactions in others, and hopefully recognize when patients need additional professional support.



While grief has been studied and evaluated on several levels, leading to some consistency in our understanding of its natural expression and rhythms, we must never forget that each person's response will be unique, as will the healing process. Our role is to recognize and acknowledge the grief, give patients permission to grieve in their own way, and provide the support they need to move forward.

*But it hurts, differently  
There is no way to predict  
How you will feel*

*The reactions of grief  
Are not like recipes  
With given ingredients*

*Each person mourns in a different way  
You may cry hysterically, or,  
You may remain outwardly controlled,  
Showing little emotion.*

*You may lash out in anger  
Against your family and friends, or,  
You may express your gratitude  
For their concern and dedication.*

*You may be calm one moment - -  
In turmoil the next.*

*Reactions are varied  
And contradictory.*

*Grief is universal  
At the same time, it  
Is extremely personal*

*Heal in your own way.*

Earl A. Grollman (1995)

## Learning Activities

### Activity 5.1 Grief Reflection Worksheet

Source: Adapted from Worden, J.W. (2008). *Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practitioner*, 4e. New York, NY: Springer Publishing Company, Inc.

#### Personal Loss History

- 1) The first death I can remember was the death of...
  - a) I was age...
  - b) The feelings I remember I had at the time were...