

Loss and Grief

Coping with the Death of a Loved One and with Other Losses Related to Huntington Disease

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Vigils I by Arthur Rimbaud,
translated by Louise Varese, from ILLUMINATIONS

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This booklet is dedicated
to the people I have known who have
died from Huntington disease

and

to my late colleague, Brigitte Rioux.

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Table of Contents

I. Introduction	6
II. Signs of Grief	7
Physical.....	7
Behavioural.....	8
Mental and Emotional.....	8
III. Stages of Grief	10
Shock.....	10
Acute Mourning.....	10
Restitution.....	10
IV. Anticipatory Grief	12
V. Grief Work	13
Social Interaction and Support.....	14
Support Groups.....	16
Leaning Into the Pain.....	16
Rituals.....	17
Counselling.....	17
Delving Deeper.....	17
Dealing with Anticipatory Grief.....	18
VI. Do's and Don'ts About Grieving	18
VII. When Is Professional Help Recommended?	19
VIII. Losses Other Than Death	20
IX. People Who Test Negative for the HD Gene	21
X. Moving Past Grief	23
XI. Conclusion	25
XII. Recommended Reading	
Books	
Research-Oriented Textbooks	
Web sites	
Articles	
XIII. Endnotes	

C'est le repos éclairé, ni fièvre, ni langueur, sur le lit ou sur le pré.

C'est l'ami ni ardent ni faible. L'ami.

C'est l'aimée ni tourmentante ni tourmentée. L'aimée.

L'air et le monde point cherchés. La vie.

— Était-ce donc ceci?

— Et le rêve fraîchit.

Veillées I
Arthur Rimbaud

It is repose in the light, neither fever nor languor, on a bed or on a meadow.

It is the friend neither violent nor weak. The friend.

It is the beloved neither tormenting nor tormented. The beloved.

Air and the world not sought. Life.

— Was it really this?

— And the dream grew cold.

Vigils I
Arthur Rimbaud
translated by Louise Varese

I. Introduction

People affected by Huntington disease (HD) experience an extraordinary amount of loss. Death, perhaps the most traumatic type of loss, comes early. (While the average Canadian can expect to live to the age of 78, it has been estimated that the average person with HD will die more than twenty years earlier, at the age of 54–55¹.) Moreover, many members of a family affected by HD will die from the disease. HD is a dominantly inherited genetic illness, so every child of a person with HD has a fifty percent chance of inheriting the illness. Many parents live to see their children die, one of the hardest forms of loss with which to cope, even if the child is an adult.

Nor is death the only loss. Before they die, people who have HD lose their jobs, professional and social roles, physical and intellectual abilities, the ability to communicate, past physical appearance, and independence. Family members also experience losses. For example, spouses may lose a companion or partner in life due to changes brought about by the illness, children may lose a well functioning parent, and families may lose a wage earner. People at risk for HD lose a sense of security about their future health and well being.

With all of this comes grief — the physical, psychological, social and spiritual reaction to a significant loss in a person's life. Grief is most commonly associated with death, but also occurs in varying degrees as a result of divorce, loss of a friendship, loss of a job, moving from one's home, or any of the major losses brought about by HD.

Grief can be very complicated, affecting your life in ways that you might not expect at the physical, mental and emotional level. Its effects can last many years, especially if you have not found a successful way to come to terms with your loss.

In our society, it is commonly believed that grief will disappear with the passage of time. Although time may help, most experts who specialise in working with people suffering from serious loss believe there are specific things you can actively do to help come to terms with your loss.

Grief is inevitable in everyone's life, and the pain of a significant loss may never entirely disappear, but an effective grieving process can allow you to move through a period of mourning instead of becoming trapped in intense feelings of depression, guilt or sadness.

As someone affected by HD — whether you have it yourself, you're caring for someone who does, or you're at risk for HD — it's particularly important for you to become familiar with effective ways of coming to terms with all losses you may be facing.

This booklet will describe grief and some of the techniques that can be used to cope with it. It will focus on grief related to death, but will also discuss non-death losses related to HD. Not all the grieving techniques described are necessary for

all people or all types of losses, but according to many experts in the field, they have stood the tests of time and experience. Research and clinical observation tend to support their use.

Try the techniques for yourself, particularly if you are having trouble getting over your loss, and discover which ones are beneficial to you. If none of the techniques prove to be helpful and if your grief is interfering with your normal way of living, consider consulting a professional, ideally someone who specialises in working with the bereaved.

You'll find lots of helpful information in this booklet. If you want more in-depth resources, check some of the recommended reading listed at the back.

II. Signs of Grief

Grief can express itself in many different ways, and every individual will experience it differently. Some signs of grief may come and go quickly, while others may last for a long time. Some may be very intense, and others only mild. However, the following signs are common,^{2,3} and you shouldn't be surprised if you experience at least a few of them, or perhaps many:

Physical

Shortness of breath

Tightness in the throat

Stomach discomfort

Numbness

Intense fatigue and lack of energy

Headaches

Sighing

Loss of weight

Dizziness

Loud heart beat

Sense of emptiness and heaviness

Increase in common illnesses like colds and flus

Physical symptoms that are the same as those of the deceased

Behavioural

A sudden loss or increase in sexual desire

Sleep and appetite disturbances

Restlessness, inability to sit

Withdrawal from friends, social situations and activities

Withdrawal from work

Excessive activity in order to distract oneself

Mental and Emotional

Absentmindedness, forgetfulness

Inability to concentrate

Preoccupation with thoughts of the deceased

Dreaming of the deceased

Auditory or visual hallucinations

Having a sense of the presence of the deceased

Shock

Anger

Disbelief

Confusion

Anxiety

Irritability

Depression

Loneliness

Panic

Guilt

Resistance to returning to normalcy

Although most people think of grief in terms of emotional reactions, physical signs of grief seem to be as just as common. The stress of loss or bereavement may also leave you vulnerable to illness.⁴ Keep in mind, however, that grief is not an illness, but a normal reaction to loss, even though it can include reactions that resemble the symptoms of a disease. If your physical signs of grief continue to last, it may mean that you haven't fully come to terms with your loss. However, you should review any persistent physical symptoms with your doctor to make sure you're not suffering from an illness.

Don't be surprised if you experience some of the mental signs of grief. After a serious loss or death of a loved one, some people believe that they are "going crazy", but this is not the case — grief can include strong psychological reactions like imagining you are seeing or hearing the deceased. These psychological reactions should decrease over time if they are dealt with appropriately.

It is common for grief to bring about changes in your spiritual self — for example, you may feel a new need to explore religion or the meaning of life, or on the other hand, you may question the existence of God after a particularly painful loss. These are reactions that pastors, priests, rabbis or other clergy have likely seen many times, so don't be afraid to discuss your issues with them.

It is also common for a new loss to bring about memories of past losses which may still need to be grieved. If your reactions seem out of proportion to your recent loss, you may need to revisit past losses and come to terms with them more completely.

One word of caution. Some of the signs of grief are easily confused with symptoms of HD: forgetfulness, depression, and irritability, for example. If you have HD or you're at risk, it might be wise to consult with a specialist to make sure these symptoms really are signs of grief.

On a final note, keep in mind that children and teenagers express grief differently from adults. Helping children and teenagers cope with loss and grief is beyond the scope of this booklet, but there are helpful resources available on the topic from the Huntington Society of Canada's National Office. You may also want to consult the excellent "Grief in a Family Context" website listed under "Recommended Reading."

III. Stages of Grief

Grief is not a static thing. Your reaction to your loss will change with time, and this is a healthy and normal process. Grief experts often describe grief in terms of stages, or patterns of change over time.

Elizabeth Kubler-Ross, a psychiatrist who studied death and dying, developed a theory that people who are going to die pass through a number of stages: denial and isolation, anger, bargaining, depression, and finally acceptance. This theory has become widely recognized, and many researchers have adapted it to describe how people deal with the death of a loved one. One of the clearest models of loss and bereavement is the following, developed by the grief experts, DeVaul and Zisook:⁵

Shock

This stage can include varying degrees of disbelief and denial, and feelings of being numb and paralysed. It may last from hours to weeks, and usually occurs around the time of mourning rites and the gathering of family and friends.

Acute Mourning

This stage begins when you acknowledge the death. It involves intense feelings, generally in periodic waves of emotional and physical discomfort. These feelings can include panic, guilt, sadness, anger and loneliness. You may withdraw from friends and family and become painfully preoccupied with the deceased. This stage may last several months.

Restitution

Restitution gradually replaces the previous stage, as you come to terms with your loss. It marks a return to well being and an ability to go on living. You begin to shift your attention back to the world around you.

It is important to remember that with any stage theory, the stages are not hard and fast; you may not necessarily experience them in the order given, and you may not experience every stage. The stages do serve, however, as a good, general description of how grief can occur and change over time.

“I felt a number of emotions immediately after my father’s death. There was a sense of relief that the struggle was over. Because we visited on a daily basis, it was emotionally draining to see him decline. When he died, we knew that this last stage was now over and that he was at peace.

There was an anger that a once-vibrant and successful businessman was reduced to a person who couldn’t understand a basic conversation. Nothing in the way that he led his life could have prepared him for this awful disease that was in his genes.

Finally, there was a profound sense of sadness. He had been in denial for so long, and then so devastated about his condition, that he never could discuss the hereditary aspect of HD and what it meant for the rest of us. He has three children and we have all tested positive for the gene. Perhaps that information would have been difficult for him to know, and made his last few years more difficult, but on the other hand it would have made it so much easier for us. We have so many questions about how he dealt with the disease, what it was really like and what he was thinking all those years.

After a while, I forgot the day-to-day visits that were so emotionally draining, and I started to remember the man that he was before the disease took over. I felt badly for him that he wasn’t able to live life to the end as he had planned, and that the last ten years had been so awful. The hereditary issues began to consume more of my thoughts, and my husband and I talked more about it with my kids.

The most difficult thing to come to terms with was the idea that I might end my life in the same way as my father. I would never want my kids to go through what we went through with Dad.”

Certain things can complicate the grieving process and prevent you from moving towards acceptance — things like unresolved issues of guilt or anger. If this describes your situation, it may be worth discussing these issues with a professional.

Pressing demands like caring for another family member can also prevent you from grieving completely. You may be too busy coping with all your day-to-day demands to even recognise the stages of grief. Although it may be difficult to create time for yourself to grieve, it’s a wise investment to make. We’ll talk about how to do that in the section on grief work.

People in families often grieve in different ways and at different rates, and it is important to respect these differences. Fathers are often the last to grieve in families. Grief can also strike in unexpected times and places.

“When I lost my sister, as estate trustee I took care of the planning of the funeral, burial, selling the house, selling the car, etc. The grief of losing my only sister hit me in my lawyer’s office while discussing a different matter ... straight out of the blue!”

Finally, keep in mind that not all deaths provoke a strong grief reaction. For example, the death of people in serious pain or of people who have been abusive may create a sense of relief.

IV. Anticipatory Grief

Anticipatory grief is grief that occurs before the actual loss. As we stated earlier, grief is not a reaction just to death, but to any significant loss in your life. Sometimes, when a person is dying from a slowly progressing illness like HD, you begin to grieve before the person dies. You may be grieving the losses you have already experienced with regard to your loved one — for example, the loss of pleasant conversation if that person can no longer speak, or the loss of support or security that that person may have provided. You may also begin to grieve the losses that you know your loved one’s death will ultimately bring, such as the loss of companionship. By the time the person close to you actually dies, you may have already completed a good deal of your grieving.

“When my father died, it brought an end to the many losses that we had grieved with him over a number of years. With him, we mourned the loss of a driver’s licence, the inability to eat the foods that once brought such pleasure, the inability to walk, the ability of self care. We died inside when he had difficulty swallowing and choked through every meal, wet his pants and had to wear diapers, and couldn’t understand even the most basic conversation.”

Although anticipatory grief may make grief at the time of death somewhat less difficult, it can also bring about other problems. Because you began to grieve months or years before, you may be less likely to participate in the beneficial rituals surrounding death. You may also struggle with guilt because you don’t feel a need to mourn at the time of death, because you may feel you detached emotionally from the dying person too early, or because you wished that the person would die soon.⁶

“What surprises me is the difficult realization that I didn’t suffer all that much grief at all after the death of my mother. And guilt because I feel I should have felt more intense grief.

My mother had HD and my father was her devoted caregiver. Thankfully, his stroke happened after she had been admitted to hospital. By that time Mother was no longer capable of much communication at all, and I used to visit her with a book so that I could just sit and read with her for a while. I sat and watched her ‘die’ for three years after my father’s death. Sadly, in my mother’s case I wasn’t able to be there, and she died alone in the middle of the night with nurses on a night shift who didn’t want to deal with it and who sounded bored when they phoned me to tell me. I felt such pity for her and wished I had been told she was ‘on her way’ so that I could get there and at least try to be with her.

I had watched my mother grieve in advance for her own losses as she progressed down her path with HD. It was a long, slow, gentle grieving that we did together over the years. When she finally died, perhaps the grief came to an end too. Perhaps I’m being poetic to cover my own guilt for not being a better advocate.”

V. Grief Work

Most people who study and work in the field of grief believe that there are certain activities you can perform that will make the task of grieving or overcoming a loss much more successful than simply waiting for time to pass. Such activities are referred to as “grief work”.

A great deal of psychological research has been conducted on grieving. Although not always as complete as one might hope, and despite some controversy, research does seem to indicate that many of the techniques recommended in current self-help books on grief can be successfully applied to most people’s grieving situations.⁷ Some recent research studies are indicating that not everyone needs to engage in grief work, and that may be true for you, but if you are having trouble coming to terms with your loss, grief work techniques may help you.

The following is a list of commonly recommended types of grief work.

Social Interaction and Support

It is widely recommended that you reach out to others and seek their support after a loss. This can involve reviewing the incidents surrounding the death with family or friends, discussing your feelings regarding the death, or at least ensuring that you are with other people and do not become isolated after the loss. Of course, individuals vary as to how much social contact they need, but the general rule is that you should be aware of and avoid any large and long-lasting increases in isolation.

At times this can be particularly challenging for families affected by Huntington disease. You may have restricted your social contact for many reasons. Years of caregiving or working long hours to support the family financially may have left you with no time for outside interests, and in addition, you may have felt reluctant to talk about the illness and its inherent problems outside the family.

If this describes your situation, it's a good idea to set at least some time aside in your pressured life for social contact. It's important to look for support beyond your immediate family, as well as within it, because other family members are also coping with loss and may not be able to be there for you as much as you need.

Accept all the help that you can from extended family, friends, home care services, respite programs for both inside and outside the home, etc. The social contacts that you develop can prove to be a great help both before and during the times of loss.

Since death is considered an unpleasant topic in our society that can make others anxious, seeking out social support shortly after a death can be a difficult task. You may find that friends withdraw or behave oddly. This is most likely because they feel uncomfortable dealing with death or because they're not sure what to say and they don't want to make you feel worse. Friends may not mention your loved one because they're afraid it will cause you pain. It doesn't mean they've forgotten or they are callous, but it may be up to you to let your friends know how they can help you.

If for whatever reason you are not receiving the social support that you need from those around you, you may have to explain to them specifically what type of help you're looking for. Running errands, helping you to sort through your loved one's belongings, cooking you meals, taking you out to a movie, listening to your anger or sorrow or pain — whatever it is you need, let them know

Bob Deits makes the following helpful suggestions on reaching out to other people in his book *Life After Loss*:⁸

Things to Tell Nongrievors

Dear (friend, parent, minister, employer ...)

I have had a devastating loss. It will take me time, perhaps years, to heal the grief that has afflicted me. For some time, it is quite possible that I will cry much more than usual. My tears do not signify weakness, a lack of hope or faith. They represent the depth of my loss and signify my convalescence.

Perhaps at times I will seem more angry than is apparently reasonable. The stress of grief tests the intensity of my emotions. Pardon me if I seem irrational.

I need your understanding and your presence more than anything else. If you don't know what to say, touch me, kiss me, but please let me know that you care about me. Please, don't wait until I call you. I am often far too tired to even think of using the telephone to reach out for the help that I need.

Don't let me become a stranger to you. Over the next year I will need your presence more than ever.

You can pray for me, but only if you don't do it through obligation. My faith should not be preventing me from grieving.

If, perhaps, you have ever experienced a grief similar to mine, share it with me. You will not hurt my feelings.

This loss is the worst thing that has ever happened to me. But I will survive and I will heal. I will not always feel the way I am feeling at this moment. I will smile again.

Thank you for thinking of me. Your consideration is a gift that I will appreciate forever.

What to Remember About People Who Aren't Grieving

Type or write the following sentences on a card or piece of paper and carry it with you during the intense time of your grief experience:

1. I will not expect others to be better at handling my grief than I would have been at handling theirs before my loss.
2. People cannot be something other than who they are.
3. Most people want to help me. They mean well even when they do dumb and hurtful things.
4. Others, including professional people, will not know what is helpful to me unless I tell them.
5. I will be as patient with others as I need them to be with me.

Support Groups

One particular form of social support is the support group. This is a group of people who get together to discuss a problem that they have in common and to share experiences and ways of coping with whatever the problem may be.

You can gain a lot of comfort being with other people who have gone through similar experiences and understand what you're feeling. Support groups can reduce what may feel like an overwhelming sense of isolation.

Another reason support groups can be beneficial is that they are often run by leaders or facilitators who are familiar with healthy grieving. This is particularly helpful if your family is affected by HD, since you may be dealing with grief at a relatively young age and both you and your peers may have little experience with losses as traumatic as that of a spouse or parent.

Grief support groups are often run by churches and other religious institutions, or by community health and social services agencies. For more information about such resources, please contact your Huntington Disease Resource Centre or Huntington Society of Canada social worker.

If an appropriate support group doesn't exist in your area, consider creating your own, whether it's formal or informal. You might be surprised by the number of people in your community eager to join. In his book *Life After Loss*,⁹ Bob Diets outlines, in great detail, recommended steps to follow in forming a support group of your own.

Leaning Into the Pain

Many grief experts believe that continually avoiding the pain of grief can cause long-term physical and emotional problems after a loss. They believe it's important to confront your loss, and this may mean exposing yourself from time to time to the source of your grief (for example, by talking about the loss, by writing about it in a journal, or by visiting the gravesite). Although the exposure may cause immediate, temporary pain, it may help you make better progress in overcoming your grief over the long term.

For some people, this technique may not be necessary, and for others it may not be helpful. There is some controversy associated with this technique, but most grief counsellors believe it can be useful. If you are having trouble recovering from your loss, you may wish to consider whether active exposure to your grief could be helpful to you.

Some people find that they are unable to get in touch with their feelings or pain associated with their grief. Exposing yourself to art, music, poetry or drama about death can be a less threatening way of eliciting feelings about the loss that you have experienced.

Be particularly careful about avoiding or dulling the pain of grief through alcohol, drugs or overwork, which will likely only postpone dealing with your loss.

Rituals

Rituals can be very helpful in dealing with loss because they provide structure at a time when the framework of your life has changed abruptly, and they give friends and family a way to acknowledge your grief. Consider using society's established grieving rituals: for example, attending funeral parlour visitations, funerals, wakes, memorial services, etc. These activities tend to make use of the ideas about grieving discussed above and have stood the test of history.

“There was no funeral whatsoever for Mother (she was clear about not wanting one). In a way I regret this. It seems uncaring just to pick up cremated remains in a shopping bag. I think funerals could help and meaningful funeral services should have been part of all three deaths in my family. It was my brother who suggested where to scatter our parents' ashes, which we did together after Mother died. We often stopped at Silver Lake on Highway 7 on our way to Peterborough from Ottawa and he suggested it because ‘it was one place where we were all happy together.’”

Some people also benefit from rituals that they create for themselves. They may set up a private shrine for the deceased in their home. They may commemorate anniversary dates by meeting with other people to talk about the deceased, for example, or visiting locations of significance to the deceased.

Counselling

Not everyone who has experienced a loss feels the need for professional help, but an experienced counsellor can help you through a difficult stage. Some people choose to enter counselling immediately after a loss, particularly after a very difficult one, like the loss of a child. Others choose counselling when grief seems unusually long lasting — for example, when feelings of anger, loneliness or guilt do not subside. Trust your own judgement and do not hesitate to seek professional help when you feel the need, especially if your grieving seems to be getting more difficult. If possible, find a counsellor who has experience in working on issues of grief and who comes recommended by a friend or professional.

The social services staff of the Huntington Society of Canada are available to provide short-term counselling for issues of grief, and they can provide appropriate referral to other counselling professionals for long-term work.

Delving Deeper

The Grief Recovery Handbook by John James and Russell Friedman (1998) describes in detail a simple, step-by-step technique that can help you resolve your grief.¹⁰ It uses many of the aspects of grief work mentioned above in a series of

specific, connected tasks. A key element of the technique involves reviewing with a friend your relationship with your deceased loved one and expressing significant emotional messages — in particular apology and forgiveness — that you were unable to deliver while he or she was still living.

Dealing with Anticipatory Grief

Remember that grief work is not just for death, but for any significant loss, and the losses related to HD are many. People with HD lose their ability to talk, to work, to walk, and to eat — to name just a few — and such losses can be grieved by all whom they affect.

Many of the grief work techniques mentioned above can also be applied to anticipatory grief. For example, you can obtain social support by discussing with others the losses that you are experiencing and anticipating with regard to a loved one who is dying, or with regard to yourself, if you are the person dying from Huntington disease. You can discuss these issues in a support group for people affected by Huntington's, or with a counsellor or social worker.

I may be helpful to express to a loved one with HD in a simple and encouraging manner any unexpressed emotional issues that remain between the two of you while the person with HD is still able to communicate well. You may also want to use taped messages and letters as a way of delivering and preserving the thoughts and feelings of the dying.¹¹

VI. Do's and Don'ts About Grieving

- Avoid making major life decisions during periods of intense grief.
- Avoid driving during periods of intense grief, and if you must drive, concentrate fully.
- Ensure you get adequate rest. Fatigue is a very common grief reaction, particularly if you took care of your loved one through a long-drawn-out illness like HD.
- Go for a complete medical check-up approximately six months into your grieving to make sure that your health is in order.¹²
- Eat well. It's easy to short-change yourself nutritionally when you're depressed and have no appetite or desire to cook, but proper nourishment will make you feel better physically and emotionally.
- Don't build a wall around yourself in fear of being hurt by a future loss — it will just make it more difficult to deal with your current loss.
- Don't expect your grief will follow a predictable path or schedule.

VII. When is Professional Help Recommended?

As noted in the “Counselling” section, professionally trained counsellors can help you to work through particularly difficult stages following your loss, and you shouldn’t hesitate to seek out their expertise.

In addition, there are certain times where there is no question that you should seek professional help — a psychiatrist, psychologist, social worker, counsellor or doctor, depending on the particular issues you’re grappling with. If you experience any of the following conditions,¹³ contact the Huntington Society of Canada, and one of our social workers or resource centres will direct you to the appropriate resources:

- Failure to be able to provide for your basic needs like washing, dressing, showering or eating.
- Persistence of one particular reaction to grief, such as an immobilizing depression* lasting several weeks, or a lack of feelings lasting several months.
- Persistent thoughts of suicide. (Thoughts of suicide during grieving are not rare, but they should pass quickly. Thoughts of specific times and ways of killing yourself are a sign to seek help.)
- Substance abuse.
- Mental illness.

If you are in doubt as to whether to seek help, err on the side of safety and consult a professional. Be sure to mention that you are grieving.

There are certain issues than can complicate your loss and may mean you’ll have more difficulty grieving it. If any of the following conditions describe your situation, and you are having a lot of trouble dealing with your grief, consulting a counsellor or psychologist might be helpful:¹⁴

- a very close, dependent, conflicted or ambivalent relationship with the deceased;
- a lack of social support;
- a past history of depression;
- current life events interfering with grieving;
- a sudden and unanticipated death;
- poor physical health; or
- substantial financial loss.

* If you have several of the following symptoms, you may be suffering from depression according to the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, 1994*:

- Depressed mood most of the day, nearly every day;
- A loss of interest or pleasure in most of the activities you used to enjoy;
- Significant weight loss or weight gain, or a decrease or increase in appetite nearly every day;
- Trouble sleeping or sleeping too much nearly every day;
- Restlessness or slowing down nearly every day, that is observable by others;
- Fatigue or loss of energy nearly every day;
- Feelings of worthlessness or excessive or inappropriate guilt nearly every day;
- Difficulty thinking, concentrating, or making decisions nearly every day; or
- Recurring thoughts of death or suicide, or a specific plan for or an attempt at suicide.

VIII. Losses Other Than Death

Up until now in this booklet, we have focused on grieving the death of a loved one, but as most people affected by HD know, death is not the only loss that is brought about by the illness. The non-death losses that you experience as a result of HD will likely be determined by your relationship to the illness.

For example, if you are at risk for HD, you will have experienced loss from the day you first learned of your status, or perhaps even earlier. You may have lost a well functioning parent because of his or her HD symptoms. You may have lost some emotional stability in your family due to a parent's psychological symptoms. You may have experienced financial losses because a wage-earning parent was no longer capable of working. You may have prematurely lost childhood innocence or an adolescent's sense of immortality and invulnerability, and lost the chance of seeing both your parents leading long, healthy lives.

If you have taken the genetic test for HD and received a positive test result, you have lost the possibility of a life free from serious illness. You may have lost the hope of having children, or of realising other dreams.

If you actually have HD, you may have lost a career, a spouse through separation or divorce, or a friend who is not able to face the illness. You may have already lost physical and intellectual abilities.

If you are the spouse of someone with HD, you may have experienced many of the losses mentioned above, although from a different perspective. And once your spouse dies, you may lose your role as caregiver and feel that some of your purpose in life has disappeared.

Grief therapists and grief researchers state that grief is a reaction that occurs as a result of any type of loss.^{15,16} So if you are affected by HD and dealing with so many losses, what can you do about the accumulated grief and the physical and

psychological reactions that are the result? Grief will not always disappear by itself. If you have not adjusted to your losses, they may also make it more difficult for you to face the death of those close to you, particularly when that death is caused by HD.

Although the topic of grieving non-death losses is not well researched, certain therapists recommend trying the types of grief work that have been described above, based on their experience with their clients.^{17,18}

With this in mind, you might consider reviewing the HD losses outlined above and seeing which ones apply to you. Also, see if you can identify other losses that are not mentioned above but that apply to your life. Reflect on how the losses that you have identified may be affecting you and consider applying the grief work techniques. Are you showing any physical or psychological signs of a grief reaction? Have you passed through any stages of grief with regard to your loss? Discuss your losses with others, particularly with people who have experienced similar losses. Support groups run by the Huntington Society of Canada are ideal for such discussion. Consider not forcing back unpleasant feelings that arise from the thought of your losses, but rather letting yourself experience those feelings and giving them the chance to diminish on their own.

If you see no way out of the sadness, anger, anxiety or other negative feelings that your losses are bringing, consider further exploration with one of the books listed in the “Recommended Reading” section below. It may also be time to seek the advice of a grief counsellor. Your Huntington Society of Canada Resource Centre or social worker can help you get the help that you need.

IX. People Who Test Negative for the HD Gene

For someone at risk for HD, finding out that you don't carry the HD gene is clearly good news. However, many people in this situation report an unexpected negative psychological reaction. It is a reaction that is unique to those who undergo genetic testing for serious illness, and it is related to grief.

If you're at risk for HD and you choose to undergo predictive testing, you've probably spent months or even years imagining the scenarios that might follow both good and bad test outcomes.

The scenarios associated with a good outcome (that is, a “gene-negative” result) usually involve many positive images such as living a long and healthy life, eradicating the risk that your children might inherit the disease, being able to get on with your goals, no longer worrying that simple physical gaffes are potential signs of HD — the list goes on.

If you've taken the genetic test and were fortunate enough to get a gene-negative test result, some of these scenarios do, in many ways, come to pass. However, you may be surprised by the amount of negative thought and emotion that you experience following the test result.

You may feel guilty that you ended up being so fortunate while many others, including people very close to you, will end up having HD. You may feel confused — at a spiritual or philosophical level — as to why you have been spared. You may agonize over the years that you feel you have worried away or wasted on negative thoughts — years during which you may have avoided setting goals because of the threat of HD. You may wonder where life will lead you now that so much has changed in an instant — the instant the geneticist announced the test result.

If this is your situation, you've lost an important part of your identity — being at risk for Huntington's. It's a significant loss. You'll need to come to terms with it, and this is not as easy as you might think. Many people assume that we only have to grieve the loss of good things, like the life of a loved one, whereas if we lose something bad, like the risk of inheriting HD, we can simply forget about it. Surprisingly, we also have to grieve the “bad” things that we lose, especially if they have played a major role in how we have lived our lives. In fact, most losses involve both good and bad aspects, and it may help to actively grieve them all.¹⁹

To actively grieve the loss of your at-risk identity, think of both the good things and bad things that you have lost. The bad things are probably pretty obvious: the risk of a devastating illness, the risk of a premature death, scaring away potential mates with your risk status, etc. There are lots of things that you can add to this list, but focus on the most serious issues.

Now try to think of the good things that you may have lost along with your at-risk identity. These may include: a major focus in your life, however unpleasant it may have been; a guiding force which pushed you to develop talents and accomplish things you might not have otherwise considered; a need to live for the moment; an intimate group of comrades-in-arms (other at-risk family members or friends) supporting each other in their common, uncertain future, a group which now does not include you. Perhaps the most difficult thing to deal with is the loss of your sense of purpose in life. Think about what you've lost and create a personal list.

Once you have reviewed both the good and bad aspects of losing your at-risk identity, it is time to consider applying some of the basics of grief work, which are covered on page 13-18. Discuss what you have reviewed with others, especially other people who are gene-negative. Confronting the negative feelings you may have had about the illness for decades can be very difficult. Pay special attention to how to cope with the good things that you have lost.

At this point you may be feeling alone and isolated, afraid to share your test results with people in your Huntington's community who have HD or continue to be at risk for the disease. Acknowledge the sadness that you may be feeling for others. It may help to think about developing a new role for yourself in the lives of people you know who are still facing the illness, along with ways to find a new focus in your life. You may have to look for and build new relationships outside the HD community.

“The doctors spoke to me about survivor’s guilt. I vividly recall laughing at them when they told me that if I tested negative, I would feel guilty. I said that would be impossible! Finally, eight months after hearing the news of my mom’s diagnosis, I went in with my boyfriend to get my own results. I tested negative. I was literally in shock and almost couldn’t walk. I had lived my life for months as if I had the disease, and in an instant I was told it was no longer a worry. Their warning of survivor’s guilt only took 20 minutes to set in. Even eight years later I ask myself questions like ‘why have I been saved from this?’ and ‘what is my purpose now?’”

Write about your thoughts and review them monthly, then yearly; see if your way of thinking changes, and see what you can learn from these changes. If you feel immobilized by your new status, consider seeking counselling.

Remember, unresolved grief can show up in ways that may not be obviously related to the loss you have experienced, so performing some grief work may prevent mysterious complications from developing later. In particular, it is important for you to grieve the loss of your at-risk identity. If you are in a family surrounded by HD, you’ll need to be emotionally strong to care for other family members and perhaps help them in their own grief, as well as deal with your own feelings as people close to you become ill with HD..

X. Moving Past Grief

It is difficult to say how long a normal period of grieving will last. It differs a great deal from person to person. Most experts estimate it takes a minimum of two years to overcome the most intense aspects of grief after a significant loss.²⁰ The loss of a child — even an adult child — may take much longer, and certain aspects of grieving may never end.

Keep in mind that your grief will likely not follow a steady course. Some days you may feel better, some days you may feel worse, and some days you may not be aware that you're feeling grieving. Certain events, like birthdays, holidays and anniversaries of a death, can trigger more intense feelings of grief, yet you may be unaware of the link. Sometimes an increase in grief will occur for no apparent reason. Such increases may be a signal to return to your grief work.

You cannot necessarily expect a complete resolution of your grief, but it should become more manageable. The loss of a loved one to death is permanent, and you may grieve certain aspects of the loss for the rest of your life. However, it is possible to regain a sense of pleasure in life.

If HD runs in your family, there will be constant reminders of your loss — the illness or death of other family members from HD, and the risk of your children, grandchildren, or nieces and nephews carrying the gene.

Remember, even though grieving may take years, you should seek professional help if you experience psychological problems like immobilizing depression or disabling anxiety for more than a couple of weeks. (Please review the previous section, entitled “When is Professional Help Recommended?” for more detail.) If you have persistent suicidal thoughts, seek help right away.

Likewise, the persistence of any physical signs that could actually be symptoms of a serious medical problem (for example, shortness of breath, loud heart beat) should also be reviewed by your doctor without delay. If in doubt, consult a professional.

Grieving can take a long time and demand patience. It is hoped, however, that the suggestions in this booklet will help you move forward in your life and assist you in working through your losses.

Remember, too, that as time passes it is okay to begin to let go of your grief and your identity as someone bereaved. For most people, life will eventually bring pleasure, new interests, and a renewed sense of purpose, and you should take advantage of these gifts when you feel ready. You will continue to change and grow as a person, and this does not mean you're being “unfaithful” to the memory of your loved one.

Rabbi Joshua Liebman sums this up nicely when he says: “The melody that the loved one played upon the piano of your life will never be played quite that way again, but we must not close the keyboard and allow the instrument to gather dust.”²¹

At times it may seem easier to stick with the familiarity of your grief than to engage in a new and changed life, but moving beyond grief, however uncomfortable it may seem at first, can bring many rewards.



XI. Conclusion

If you have been affected by Huntington disease, you unfortunately have encountered or will encounter an extraordinary amount of loss in your life. Whether you are at risk for HD, actually have HD, or have a close relationship with someone else who has HD, you cannot escape the innumerable losses and premature deaths that result from this illness, nor can you escape your grief.

This booklet summarizes a number of activities that have been recommended by experts in grieving, and which can be used to help you come to terms with loss and grief related to Huntington disease. Although not everyone needs to use grief work activities, it is hoped that if you do try them, they will be helpful to you.

This booklet is intended as an introduction to grief work. The books and articles listed under “Recommended Readings” provide much greater detail and exercises that will make your grief work even more effective. These books, and other books on the topic of grief or grieving, can be purchased or ordered at your local bookstore, or borrowed from your local library, or perhaps from your Huntington Disease Resource Centre. You will be amazed at the resources you will find on the topic in most bookstores. Many bereavement organizations also have lending libraries. Your HD Resource Centre or Huntington Society of Canada social worker can direct you to such organizations in your part of the country. The articles are available from the National Office of the Huntington Society of Canada.

Remember, if you are ever in doubt about the progress you are making in your grieving, consult a professional. This may be a psychiatrist, a psychologist, a clinical social worker, clergy, or a member of the Huntington Society of Canada social services team. Ideally it should be someone who is recommended to you and someone who has experience in grief counselling.

XII. Recommended Reading

Books

Deits, Bob. *Life After Loss — A Personal Guide Dealing with Death, Divorce, Job Change and Relocation*. Fisher Books, 2000.

James, John W., and Russell Friedman. *The Grief Recovery Handbook*. Harper Collins, 1998.

Monbourquette, Jean. *To Love Again — Finding Comfort and Meaning in Times of Grief*. Novalis, 1993.

Viorst, Judith. *Necessary Losses — The Loves, Illusions, Dependencies and Impossible Expectations That All of Us Have to Give up in Order to Grow*. Fawcett Gold Medal, 1986.

O'Toole, Donna. *Aarvy Aardvark Finds Hope — A Read Aloud Story for People of All Ages about Loving and Losing, Friendship and Hope*. Mountain Rainbow Publication, 1988.

Research-Oriented Textbooks:

Rando, Therese A. *Grief, Dying and Death — Clinical Interventions for Caregivers*. Research Press Company, 1984.

Stroebe, Margaret S., Wolfgang Stroebe, and Robert O. Hanson, eds. *Handbook of Bereavement: Theory, Research and Intervention*. University of Cambridge, 1993.

Websites

www.indiana.edu/~fmlygrf

“Welcome to Grief in a Family Context” — Transcripts from 14 lectures by Kathleen Gilbert of Indiana University.

Articles

The following articles may be ordered from the National Office of the Huntington Society of Canada. Please call 1-800-998-7398.

“Anger” Can be Expressed
compiled by Bonnie Bright, Holy Cross Hospital Grief Center, S.L.C. UT. 1992
(reprinted with permission from Bereaved Families of Ontario)

Beyond Grief: Surviving a Suicide
(reprinted with permission from Bereaved Families of Ontario)

Death and the Workplace
(reprinted with permission from Bereaved Families of Ontario)

Experiences of Grief

(reprinted with permission from Bereaved Families of Ontario)

Helping Yourself When Your Spouse Dies

by Jimmie L. Radliff. Permission to reprint from Thanatos, Fall 1993 Vol.18/No.3

(reprinted with permission from Bereaved Families of Ontario)

Hope For Survivors. Those whom suicide leaves behind

(reprinted with permission from Bereaved Families of Ontario)

How Do We Tell The Children? What children think about death

Daniel Schafer and Christine Lyons

(reprinted with permission from Bereaved Families of Ontario)

How To Comfort a Loved One When Death is Near

(reprinted with permission from Bereaved Families of Ontario)

How To Help Grieving People

(reprinted with permission from "Hope for Bereaved")

How To Help Ourselves Through The Holidays

Donna Kalb

(reprinted with permission from Bereaved Families of Ontario)

Losing An Adult Child

From "Time to Remember" by Barbara Klich

(reprinted with permission from Bereaved Families of Ontario)

On Dealing With Loneliness

(reprinted with permission from Bereaved Families of Ontario)

Suggestions For Coping With Depression

(reprinted with permission from "Hope for Bereaved")

Suggestions For Handling Guilt

(reprinted with permission from Bereaved Families of Ontario)

Suggestions for Helping Yourself Through Grief

(reprinted with permission from "Hope for Bereaved")

Symptoms of Grief

(reprinted with permission from Bereaved Families of Ontario)

The Death Of A Grandparent

Laurie Konwinski

(reprinted with permission from Bereaved Families of Ontario)

Things to Keep in Mind When Working with Bereaved Teens

(reprinted with permission from Bereaved Families of Ontario)

Through A Father's Eyes

From "Time to Remember" by Barbara Klich

(reprinted with permission from Bereaved Families of Ontario)

Ten Stages of Grief

Adapted from *Good Grief* by Granger E. Westberg, copyright 1962, 1971
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(www.augsburgfortress.org)

What Teachers and School Personnel can do to Help Grieving Students
(reprinted with permission from “Hope for Bereaved”)

When A Parent Dies

Mark T. Scrivani

(reprinted with permission from Bereaved Families of Ontario)

When a Sibling Dies

(reprinted with permission from “Hope for Bereaved”)

XIII. Endnotes

- ¹ P.S. Harper. *Huntington Disease*. (London: WB Saunders, 1996). Michael Hayden. *Huntington's Chorea*. (Berlin: Springer-Verlag, 1981).
- ² Bereaved Families of Ontario — Ottawa-Carleton, "Symptoms of Grief" (Ottawa: Bereaved Families of Ontario — Ottawa-Carleton).
- ³ Grange E. Westberg, *Good Grief* (Philadelphia: Fortress Press, 1971).
- ⁴ Margaret S. Stroebe, Robert O. Hansson and Wolfgang Stroebe, "Contemporary Themes and Controversies in Bereavement Research," in *Handbook of Bereavement: Theory, Research, and Intervention* (Cambridge: Cambridge University Press, 1993).
- ⁵ Stephen R. Shuchter and Sidney Zisook, "The Course of Normal Grief," in *Handbook of Bereavement: Theory, Research, and Intervention* (Cambridge: Cambridge University Press, 1993).
- ⁶ Therese A. Rando, *Grief, Dying and Death — Clinical Interventions for Caregivers* (Champaign: Research Press Company, 1984).
- ⁷ Margaret S. Stroebe, Wolfgang Stroebe and Robert O. Hansson, "Bereavement Research and Theory: An Introduction to the Handbook," in *Handbook of Bereavement: Theory, Research, and Intervention* (Cambridge: Cambridge University Press, 1993).
- ⁸ Bob Deits, *Life After Loss: A Personal Guide to Dealing with Death, Divorce, Job Change and Relocation* (Cambridge: Fisher Books, 2000).
- ⁹ Bob Deits, *Life After Loss: A Personal Guide to Dealing with Death, Divorce, Job Change and Relocation* (Cambridge: Fisher Books, 2000).
- ¹⁰ John W. James and Russell Friedman, *The Grief Recovery Handbook* (New York: Harper Collins Publishers Inc., 1998).
- ¹¹ Richard S. Atwell, "Diagnosis: Terminal Illness," in *Gulf Coast Christian Newspapers*.
- ¹² Bob Deits, *Life After Loss: A Personal Guide to Dealing with Death, Divorce, Job Change and Relocation* (Cambridge: Fisher Books, 2000).
- ¹³ Bob Deits, *Life After Loss: A Personal Guide to Dealing with Death, Divorce, Job Change and Relocation* (Cambridge: Fisher Books, 2000).
- ¹⁴ Stephen R. Shuchter and Sidney Zisook, "The Course of Normal Grief," in *Handbook of Bereavement: Theory, Research, and Intervention* (Cambridge: Cambridge University Press, 1993).
- ¹⁵ Paul C. Rosenblatt, "Grief: The Social Context of Private Feelings," in *Handbook of Bereavement: Theory, Research, and Intervention* (Cambridge: Cambridge University Press, 1993).
- ¹⁶ Colin Murray Parkes, "Bereavement as a Psychosocial Transition: Processes of Adaptation to Change," in *Handbook of Bereavement: Theory, Research, and Intervention* (Cambridge: Cambridge University Press, 1993).
- ¹⁷ John W. James and Russell Friedman, *The Grief Recovery Handbook* (New York: Harper Collins Publishers Inc., 1998).
- ¹⁸ Bob Deits, *Life After Loss: A Personal Guide to Dealing with Death, Divorce, Job Change and Relocation* (Cambridge: Fisher Books, 2000).
- ¹⁹ John W. James and Russell Friedman, *The Grief Recovery Handbook* (New York: Harper Collins Publishers Inc., 1998).
- ²⁰ Margaret S. Stroebe, Robert O. Hansson and Wolfgang Stroebe, "Contemporary Themes and Controversies in Bereavement Research," in *Handbook of Bereavement: Theory, Research, and Intervention* (Cambridge: Cambridge University Press, 1993).
- ²¹ Joshua Liebman, *Peace of Mind* (New York: Simon & Schuster, 1946).

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