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Module 5 : Session 1 : Printed Instructions “Understanding Grief” PDF

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“Understanding Grief” Module 5, Session 1

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“Grief after Death”

Complete Workbook Page 16-17

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Read Action Step

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Finish Button

Coping with Grief

Applying the three steps of Creative Indifference to your experience with grief, complete the following statements:

I am **AWARE** that I am grieving things we have already lost, including _____

There are things I expected to have - and things I thought we'd be doing right now that are no longer possible. I am grieving the loss of

I **ACCEPT** that Preparatory Grief is painful process. This situation will most likely get worse before my role as a caregiver ends. I expect as we go forward that I will have to adjust to

Action steps to cope with Preparatory Grief

I will take a mental and physical inventory. (Check all items that apply)

I am currently experiencing . . .	
<input type="checkbox"/> Anger	<input type="checkbox"/> Change in Weight
<input type="checkbox"/> Guilt	<input type="checkbox"/> Difficulty sleeping
<input type="checkbox"/> Tension	<input type="checkbox"/> Loss of objectivity
<input type="checkbox"/> Headaches	<input type="checkbox"/> Feelings of sadness
<input type="checkbox"/> Backaches	<input type="checkbox"/> Depression

Knowing that grief is not a linear process and that time alone will not heal my pain, I will be patient with myself, and I will seek comfort and accept help from:

- Family _____
- Friends _____
- Support Group _____
- Professional Counselor or Clergy _____
- Physician _____
- Education/ Conferences _____
- Exercise _____
- Favorite Activity _____
- Grief Counseling Program _____
- Other _____

I will allow myself to grieve my losses, and if I reach a point where the weight of my losses feels overwhelming or unbearable, I will seek help from _____

Self-care is not selfish:

Understanding ‘preparatory grief’ and making plans for you



By Elaine K. Sanchez

When visiting with my friend Joyce recently, after inquiring about her husband’s latest cancer treatment, I asked “And how are you doing?”

She said, “You know, I’m okay. Three years ago when Mark got the diagnosis I was overwhelmed with grief. I couldn’t get past the idea that my husband was going to die. And then our lives were taken over by doctors’ appointments and hospital stays and the dreadful side effects he suffers as a result of all the treatments. A few weeks ago, I finally accepted the fact that he is going to die before I do. I can’t continue to put my life on hold until his is over, so **I’ve decided that I am going to keep on living. I’ve started exercising and taking better care of myself, and I’m beginning to make plans for how I will go on after he dies.**”

For anyone unfamiliar with the term “preparatory grief,” Joyce’s words may sound a bit callous. But if you have gone through a long illness with a loved one, you probably understand that Joyce has gone through a lot of denial, anger, guilt and sadness before reaching this point of reality and acceptance.

Constantly adjusting

Preparatory grief is the process we go through when we are losing a loved one to a progressive, degenerative and ultimately fatal disease. It is different from the grief people experience when

a loved one dies, in that it requires constant adjustments to ongoing changes and losses.

My mother cared for my dad for six years following his debilitating stroke. One of the ways she coped with her grief was to disengage her emotional monitor and write letters to me in which she described everything she was experiencing and exactly how she felt about it. In one letter, written about four years after Dad’s first stroke, she said, “I think when a person has a sick husband or wife, it can feel as if you’ve been alone for the same number of years that person was sick. I have said many times that my husband died on October 30, 1993. We just haven’t gotten around to burying him yet.”

When she wrote this, she was grieving the loss of the man my father had been before his stroke. She was grieving the relationship they once had and would never have again. She was grieving the life she had expected to be sharing with him at that point in their marriage, and the losses she knew were still ahead of her.

What’s going on?

According to Dr. Virginia Tyler, a grief counsellor with Evergreen Hospice in Albany, Oregon, it is not unusual for persons experiencing preparatory grief to feel both physically and emotionally upset.

Common physical responses experienced by caregivers during preparatory grief include:

- difficulty sleeping
- lack of energy and irritability
- change in appetite, with weight gain or loss
- physical ailments such as headaches, stomach aches, intestinal problems or back and shoulder pain

Moving forward

Acceptance comes when the caregiver is able to develop a realistic understanding and expectation of the situation. It does not always come easy. **Acceptance takes time as well as a lot of mental and emotional effort.** It can help to realize the following:

- It's difficult to maintain balance in a constantly changing situation.
- You are powerless over certain aspects of your loved one's condition.
- It is possible to experience personal, emotional and spiritual growth while caring for a terminally ill loved one.

How you cope will vary based on your relationship with your loved one before the illness and the severity and duration of the condition. Other things that are happening in your life, including your health, family, work and friends, will also determine how you cope with loss and change.

Dealing with behavioural changes

As a disease progresses, you may witness changes in your loved one's personality. Nothing will make this process easy or painless, but here are five suggestions that might

help you manage your feelings of frustration as you go through the caregiving experience and preparatory grief:

1. Separate the disease from the person

Caregivers often mistakenly think their loved one is being difficult on purpose. Pain and dementia are two factors that can dramatically alter a person's behaviour. When in pain, someone who has always been cheerful and optimistic can become demanding and sour. A stroke survivor who has been active and self-reliant his entire life may suddenly seem moody and lazy. Persons with Alzheimer's and other dementia-related diseases frequently become stubborn and combative.

If you are witnessing these types of changes, talk to the doctor. Find out if the challenging behaviour is typically associated with the disease. If it is, then blaming the disease rather than your loved one may save you both a lot of negative emotional energy.

2. Focus on a happy memory

Try to recapture the positive feelings you had for your loved one when you shared a specific positive experience. Remember how you felt toward the person in that moment. Then, when you are feeling exceptionally angry, upset or sad, pull that memory out and focus on trying to replace your current negative mental energy with the positive feelings you recall.



“If you can afford to go First Class and don't, your heirs will!”

Unknown



During preparatory grief, many caregivers experience denial, anger, guilt and sadness before reaching a point of acceptance.

Denial can manifest as:

- a tendency not to see the loved one's condition realistically
- hoping that changes will not be progressive or permanent
- reluctance to recognize decline and advance to a new level of appropriate care

Anger can be directed toward:

- the disease and the care receiver
- the medical community and community services
- friends and family members who don't offer help or support, and/or say or do unhelpful or hurtful things

Guilt may be experienced:

- for having negative thoughts and feelings toward the care receiver
- over getting angry or impatient
- for wishing a loved one's suffering would end

Sadness is felt toward:

- an overwhelming sense of loss for your former life
- knowing that the future you had planned is no longer a possibility
- regretting what your loved one is missing as his or her illness progresses

“Don't cry because it's over; smile because it happened.”

Dr. Seuss

If you didn't have a good relationship before the illness or accident and don't have a bank of happy memories from which you can draw, think of a time that your care receiver presented you with a difficult challenge that you handled well. Focus on the positive feelings you had about yourself in that situation and use that experience to help you deal with new challenges.

3. Meet your loved one where he or she is right now

Dorothy Tucker, a nurse who worked in nursing homes and on Alzheimer's units for 30 years, said she thought the main difference between family caregivers and professional caregivers is that professional caregivers do not grieve the loss of who the person used to be. She said, "As a nurse on an Alzheimer's unit, I didn't feel sad about how the resident had changed. I never mourned who they had been 10 or 15 years earlier. I just loved them for who they were when I was with them."

Good memories are precious. Hold them in your heart, and understand that Alzheimer's

and other dementia-related diseases may permanently steal those experiences from your loved one's mind. Blaming the disease instead of your loved one can make it a lot easier on you both.

4. Join a support group

Caring for an aged, chronically ill or disabled loved one is perhaps the most incredibly difficult and generous act any of us will ever perform on behalf of another. People who have not done this work cannot possibly understand the physical demands or the emotional stress

involved. Joining a caregiver support group can provide you with a safe place to express all your emotions. You will learn that having negative and angry feelings doesn't make you a bad person.

When you give yourself permission to be human, it relieves a lot of pressure.



5. Create a plan for self-care

When we are in the process of losing someone we love, it creates an aching, gaping hole in our heart. The pain inflicted by this emotional wound can be as intense as any physical injury. No one else has the same relationship with your loved one as you do, and no one will ever fully be able to understand your sorrow. Your loss and your path to healing are totally unique.

Although there are no shortcuts or one-size-fits-all solutions to going through preparatory grief, it will help if you can accept the fact that self-care is not selfish. If you take care of your body and pay attention to your mental, emotional and spiritual needs, you will be in a better position to help your loved one now. And, like my friend Joyce, you may be able to start imagining a life after caregiving. ●



Elaine K. Sanchez is a healthcare speaker who is passionate about helping others cope with the emotional stress of caregiving. Visit her website at:

<http://EKSanchez.com>

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