Caring for the Caregiver

Resource Book

A Program of Hospice of Northwest Ohio

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“Said one oyster to a neighboring oyster, I have a very great pain within me. It is heavy and round and I am in distress.’

And the other oyster replied with haughty complacence, ‘Praise be to the heavens, and to the sea, I have no pain within me! I am well and whole both within and without.’

At that moment a crab was passing by and heard the two oysters, and he said to the one who was well and whole both within and without, ‘Yes, you are well and whole; but the pain that your neighbor bears is a pearl of exceeding beauty.’

- unknown
Caring for the Caregiver

Our purpose is to affirm persons who are caregivers in their challenging situations, and to offer information and encouragement that will help caregivers take excellent care of themselves so they can continue to provide excellent care for their loved ones.

Please don’t make any significant life changes to your exercise patterns or diet without consulting your health professional. And, if you are feeling down and can’t find hope / joy – please consult your health professional immediately.

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Other Programs That Can Help

In addition to our Caring for the Caregiver classes, Hospice of Northwest Ohio provides a variety of other free community resources that assist patients and their families before, during and after a serious illness. They include:

**Hands-On Caregiving** – This two-hour workshop offers caregivers the information they need to confidently provide hands-on, physical care for their loved ones. Through discussion and interactive demonstrations, family caregivers learn ways to best handle bed baths, changing a brief, making a bed with someone in it, transferring, etc.

**Bereavement Support** – A variety of free support services are offered to anyone in the community, whether or not their loved one died on the Hospice of Northwest Ohio program. Services include one-on-one counseling, support groups and special workshops which help people of all ages adjust to the loss of a loved one. All support group meetings are conducted by professional counselors and are held at either our Toledo or Perrysburg Hospice Centers or our Michigan Office.

**Advance Care Planning** – In conjunction with the Advance Care Planning Coalition of Greater Toledo, this program assists in the completion of advance directives, such as Living Wills and Durable Powers of Attorney. It encourages people—at any stage of life—to have meaningful conversations with their loved ones about their wishes for treatment before a health crisis occurs and they are unable to speak for themselves.

**OUR PRIMARY SERVICES:**

**Hospice of Northwest Ohio** – Hospice care is provided to persons with any terminal illness or late-stage chronic illness who have a life expectancy of six months or less and are no longer seeking curative treatment. Comprehensive care—as well as all medicines and medical equipment needed to manage the terminal illness—are provided wherever patients call home. When pain and symptoms are acute, our home-like Hospice Centers provide inpatient care. Covered by Medicare, Medicaid and most health insurance plans, no one is turned away due to ability to pay or the complexity of their care needs.

**Sincera Supportive Care and Symptom Relief** – This home-based palliative care program provides pain and symptom management consultations for patients with serious illnesses, whether they expect a full recovery or are continuing to decline. They may still be seeking curative treatment. This service is also covered by insurance.

If you have any questions or need additional information, please call **419.661.4001** or visit: [www.hospicenwo.org](http://www.hospicenwo.org); [www.straight-answers.org](http://www.straight-answers.org); or [www.sinceracare.org](http://www.sinceracare.org).
A Caregiver’s Bill of Rights

- Jo Horne, Author of CareGiving: Helping an Aging Loved One

I have the right . . .

- To take care of myself. This is not an act of selfishness. It will give me the capacity of taking better care of my relative.
- To seek help from others even though my relative may object. I recognize the limits of my own endurance and strength.
- To maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things for myself.
- To get angry, be depressed and express other difficult feelings occasionally.
- To reject any attempt by my relative (either conscious or unconscious) to manipulate me through guilt, anger or depression.
- To receive consideration, affection, forgiveness and acceptance for what I do for my loved one for as long as I offer these qualities in return.
- To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my relative.
- To protect my individuality and my right to make a life for myself that will sustain me in the time when my relative no longer needs my full-time help.
- To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired older persons in our country, similar strides will be made toward aiding and supporting caregivers.
- To ________________________________________________ (add you own statement of rights to this list. Read the list to yourself every day).
Care

What does it really mean to care?
What is effective caregiving?
True care is not ambiguous;
It excludes indifference and is the opposite of apathy.
The word care is from the gothic kara which means lament.

To truly care is to grieve with, experience with, sorrow with, cry with another.
True care is not something provided to the weak by the strong,
not something given the powerless by those with power,
not something donated from the “haves” to the “have-nots”.

When people tell me who has meant the most to me,
It usually is not one who has given advice, solutions, or cures.
Most often, the person most cherished is one who chose to share in the loss and the pain
And touch the wounds with gentle love.
A cherished caregiver seems to be one who is silent with us
In our moments of despair or confusion and has simply been with us
in time of grief and bereavement.

A true caregiver becomes a cherished friend in being able to tolerate with us
Not knowing, not curing, not healing,
Helping us to face the reality of our powerlessness.
This is a true friend that cares.

A true caregiver knows that being fully present to each other is what really matters.
It matters more than the loss experienced.

A true caregiver becomes a cherished friend
By entering deeply into our suffering while being present to his own.
True care,
This is being present.
True caregivers,
Thus, listen,
Accepting the bereaved as we are,
Encouraging us
To trust
In ourselves
And
In our Creator.

- unknown
“The longer I live, the more I realize the impact of attitude on my life. Attitude, to me, is more important than facts. It is more important than the past, than education, than money, than circumstances, than failures, than successes, than what other people think or say or do. It is more important than appearance, giftedness or skill. It will make or break a company… a church… a home. The remarkable thing is we have a choice every day regarding the attitude we will embrace for that day. We cannot change our past… we cannot change the fact that people will act in a certain way. WE cannot change the inevitable. The only thing we can do is play on the one string we have, and that is our attitude… I am convinced that life is 10% what happens to me and 90% how I react to it. And so it is with you… we are in charge of our attitudes.”
If You Were A Car

As a caregiver, you spend so much time thinking about, caring for and loving others that you might forget that you too need love and care. Sometimes caregiving becomes so complex, and you give so much of yourself, that you don’t even know when you are running on empty.

If you were a car, what would your gas gauge read?

   Empty      ¼ full      ½ full      ¾ full      Full

What used up your gas?

Running on empty prevents you from getting to where you need to go. If you don’t care for yourself, you may have difficulty caring for the care receiver. What could you do for yourself that would fill your gas tank?

In the following space, write one thing that gives you comfort, joy or sustains your ability to get around in the world of caregiving. It can be as simple as taking 5 minutes during the day to sit down and put your feet up, or something as grand as going out to lunch for an hour with a friend. Try to do it within the week.

One thing I can do for myself this next week:

   Place your car where you can see it every day to remind you to fill your gas tank and give your car a tune up!

Adapted from the Hospice of the Florida Suncoast – Module 1- SA8 2003
10 Traits of Emotionally Resilient People - www.heartmath.com

1. **They practice the art of care and self-care.** They have discovered what their personal needs are and they provide for themselves. They have taken the time to discover and incorporate whatever it is that makes them feel cared for; creating a baseline and individual strategy.

2. **They understand that stressful situations don’t define them.** They have relegated circumstances to their rightful place: as short-term conditions that have no power or influence over whom they are in the moment or who they will be when the situation has changed.

3. **They are compassionate.** They know that everyone deserves respect, good will and love — including others who may not be handling situations or circumstances in ways they would prefer. Judgment and condemnation do not contribute to nurturing resilience.

4. **They know life isn’t perfect and they’ve learned to practice acceptance.** Instead of resisting what is happening, even if it’s not their preference, they accept circumstances they can’t change and expect that things will get better.

5. **They know when to ask for help.** We’re taught to be self-reliant and independent with our problem-solving and much of the time this approach is entirely appropriate. Yet sometimes the best way to the downhill side of a challenge is to enlist the help of friends, family or colleagues. Resilient people have learned discernment in making this choice.

6. **They know when to listen, when it’s time to be supportive, and when to allow space.** These are also judgment calls. Holding the awareness that there is a right time and circumstance for each of these strategies is the first step to learning which one is applicable in any given situation.

7. **They have positive supportive circles.** Making a conscious choice to interact with people who are willing and able to offer the support they need is vital in building resilience. Negativity and criticism drain resources and impact the ability to put things in perspective.

8. **They know who to go to for honest advice and who’s more likely to add drama to a situation.** Loving or caring for someone doesn’t necessarily mean that person will provide
the guidance you need. Each person has his/her own strengths, so taking relevant personality traits into consideration before asking for advice is important.

9. **They are self-aware and often engage in practices that provide self-reflection.** The adage of “know thy self” is important in building and living with resilience. It can often make the difference between feeling confidence about the ability to handle adversity and feeling hopeless or overwhelmed.

10. **They are grateful.** They often have a gratitude practice that they do daily — such as keeping a gratitude journal. Gratitude broadens perceptions about life and helps to increase feelings of hope and openness towards new possibilities.

It's common to have developed several of these traits, yet have little experience or comfort with others on the list. Zero in on which areas you feel can assist in boosting your reservoir of resilience. You'll find it's worth the effort and focus so you can achieve the results you are looking for.
Look on the Bright Side

We often measure the value of what we do through feedback and words of appreciation or compliments expressed by others. Finding the inner voice that supports who you are and what you do can be more effective in helping you gain confidence as a caregiver and value yourself. As a caregiver, you may be in a situation where your friends or others do not know what you do as a caregiver or are not present when you need affirmation. Perhaps your care receiver is unable to verbalize appreciation or is too ill to provide the positive reinforcement that you may need to feel good about your role as a caregiver. It may be up to you to acknowledge and affirm who you are and what you do well. Like many things in the world of caregiving, “If you don’t do it, it may not get done.”

By focusing on the bright side, you can find greater satisfaction in the caregiving experience. Positive affirmations will sustain you and bring out the best in you during challenging situations. It is often difficult to compliment yourself or pat yourself on the back for the good things you do and for the person you are, but practice will help you to become more comfortable letting your inner voice provide the support, encouragement and acknowledgement for who you are and a job well done.

The following exercise is intended to help you practice looking at the bright side and acknowledging and appreciating who you are and what you do. You can choose to either answer the questions by responding verbally to yourself or writing your answers on the page.

Adapted from the Hospice of the Florida Suncoast – Module 6- SA1 2003
List the three things you like about yourself.
1.
2.
3.

List the three things others like about you.
1.
2.
3.

List three things you do very well.
1.
2.
3.

List three things you have learned to do since becoming a caregiver.
1.
2.
3.

Now look at your answers.

Did you look on the bright side of who you are and what you do?

Adapted from the Hospice of the Florida Suncoast – Module 6- SA2 2003
Things People Need to Thrive by Janet Miller MA LPCC

1. Adequate rest
2. Nutrition
3. Exercise – fitness
4. New learning – positive in….
5. Creative repetitious motion – a hobby!
6. Unconditional relationship
7. Spirituality
8. Positive thoughts/brain

The more of these I have in my month, the healthier I am. The more I have in a week, the healthier I am. The more I have in my day, the healthier I am.
Coping Ideas

1. “Things People Need to Thrive”
2. Schedule time for yourself
3. Monitor your mindset
4. Acknowledge your emotions – contain but don’t deny… may want to “save them” as work for later
5. Ask self if this opportunity or response is fear based or love based
6. Remember / remind yourself why you do what you do
7. Create a personal space in your home… a sort of retreat
8. Choose positivity – always replace negative with positive …. Don’t list what didn’t get done… list what DID get done
9. Don’t “should” on yourself
10. Journal / write letters
11. Talk
12. Maintain your identity – nurture yourself… what nurtures your soul – causes personal growth, or excites you … do that at least sometimes
13. Visit your physician as YOU need to
14. Set limits – boundaries
15. Delegate / share work… on purpose
16. Say “NO”
17. Get help – with chores, and through support groups or counselors or pastors or friends
18. Prayer or meditation
19. Take breaks and LAUGH
20. Relax – do something you enjoy – for a week or even moments at a time
21. On purpose do things that are creative repetitious motion – get a hobby
22. Figure out what things bring you comfort and delight and make time
23. Unplug / step away from electronics for moments or an hour or more as you are able
24. Buy time – outsource – pay for care if possible… so you don’t have to “do it all”
25. Listen to music
26. Take power naps
27. Lift weights or go for a walk or run, if you are able
Caregiver Stress

“I can’t remember the last time I had a day to myself.”

“I try to take good care of Mom and also find time for my husband and children, but there is not enough of me to go around.”

Stress is part of life for everyone and a certain amount of stress is useful. Without deadlines, many tasks would never get done. But if you are balancing family and work responsibilities in addition to caring for a loved one, stress can quickly reach harmful levels.

Concern about the decline of your loved one and your lack of control over what is happening can be very stressful. Another stressor may be the amount of time and energy you spend caregiving. If your loved one lives with you, you may resent your loss of privacy and the many adjustments you make.

Your past and present relationship with your loved one will influence how stressful caregiving is for you. You can start by acknowledging your feelings. All feelings are legitimate, even those that are disturbing to you, including anger, frustration, and sadness. Your feelings have a lot to do with the way you cope with the challenges of caregiving.

Complete the following checklist to get a handle on your stress. **Answer each statement with seldom true, sometimes true, often true, or usually true**

- _________I don’t get enough rest.
- _________I don’t have enough time to myself.
- _________I don’t have time to be with other family members.
- _________I feel guilty about my situation.
- _________I don’t get out much anymore.
- _________I have conflicts with the person I care for.
- _________I have conflicts with other family members.
- _________I cry or feel sad.
- _________I worry about money.
- _________I don’t have enough experience or knowledge to give good care.
- _________I don’t feel well.
- _________I have trouble sleeping.
I am eating much more or much less than usual.
I use alcohol or other drugs to cope.
I can’t concentrate at work.

If you responded usually true or often true to one or more of these statements, it is time to make some changes and reduce your level of stress.
A thought is...

"If you understand something, you can control it instead of allowing it to control you."

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**STIMULATION** (from either internal thinking or external - 5 senses)

- **THALAMUS / HYPOTHALAMUS**
  - Memory "Trees"
  - (the brain of the endocrine system)

- **AMYGDALA**
  - Library of emotional perceptions

Both are looking in the "trees" and in the "books"
For familiar/similar to put this new stimulation with

**NEGATIVE EMOTIONS ALWAYS OVERRIDE POSITIVE HERE.**
Amygdala has stronger connection back to Thalamus than Thalamus to Amygdala - so **EMOTIONS ALWAYS RULE LOGIC.**

- **BIOCHEMICALS** - peptides, hormones, etc.
  - are released in response to the ☄️ or the ☁️ emotional state

- **HIPPOCAMPUS**
  - Holds incoming information for 48-72 hours while
  - Corpus Callosum "thinks/analyzes" new stimulation
  - and decides to accept or reject it

- **HYPOTHALAMUS**
  - Makes a new "tree/memories"

- **BIOCHEMICALS** continue to be sent out - washing over all of the cells of the body, constantly affecting them ☄️ or ☁️
A thought is...

**Stress Response**

When a **NEW STIMULI** comes in, immediately it is connected with the trees/memories and the books/emotions and **BIOCHEMICALS** are released. So, we can do “fight or flight” if necessary.

- **Thalamus**
  - $\rightarrow$ **CRH** = “neuropeptide of negative expectation”
  - $\rightarrow$ **Pituitary**
    - $\rightarrow$ **ACTH** = “fear hormone”
    - $\rightarrow$ **Adrenals**
      - $\rightarrow$ **Adrenaline and Corticosteroids** (cortisol)
      - $\rightarrow$ Increased blood glucose for energy to “fight or flight”

If this stressor is never relieved by rejecting the thought/stimulation, or not resolved:

- **CORTISOL AND OTHER BIOCHEMICALS**
  - $\rightarrow$ Weight gain, bone demineralization, decreased memory, decreased motivation, decreased joy and **ANXIETY** set in.

**So WE add “COMFORT FOODS”**

**Short term:** Uplifting.

**Long term:** Precipitation of downward spiral of negative feelings. Carbohydrates anesthetize the mind and dull the thinking process by acting as a blanket that prevents you from listening to all the good news your peptides might be telling you.
How to Detox Your Thoughts  Dr. Caroline Leaf and others

STEP 1 - CONSCIOUSLY CONTROL YOUR THOUGHTS
**This is not just the first step in the process - it is the MAIN STEP.
ASK YOURSELF...
1. Were “could-haves,” “would-haves” or “should-haves,” “If onlys” part of your inner vocabulary today?
2. How many times have you replayed a conversation or situation in your head that pained you?

Dr. John Sarnos says... “Thoughts do cause illness and should thus be studied and controlled” BUT --- “If they are powerful enough to make us sick, they are powerful enough to make us healthy as well.”

“Consciously controlling your thought life means not letting thoughts rampage through your mind, but learning to engage interactively with each one. Your job is to analyze a thought before you decide either to accept or reject it.” (Leaf “Who Switched Off My Brain”)
- How do you do this? By “looking” at your mental processes - this is essential.

Common unrealistic things people believe:
1. “I must do well”
2. “You must treat me well”
3. “The world must be easy, just / fair.”
- Ditch unrealistic thinking. - Thoughts create your mood

Techniques for controlling your thought life:
1. Understand how a thought forms.
2. Use your brain’s “strainer” - actively analyze incoming information and thoughts.
3. Make a conscious decision to accept or reject a thought. Only keep the ☺
4. Never let thoughts just wander through your mind unchecked.
5. Deal with emotional strongholds and build strong memory.

STEP 2 - FRAME YOUR WORLD WITH YOUR WORDS
WORDS = electromagnetic life forces that come from a thought inside your brain and are influenced by your five senses. They contain power and work hand-in-hand with your thought life, influencing the world around you and the circumstances of your life.

STEP 3 - EXPRESS EMOTIONS
Example - the closet stuffed full before guests arrive...and then explodes.
- Signs of suppressed emotions = irritability, short temper, over-reactivity, anxiety, frustration, fear, impulsivity, a desire for control, perfectionism, self-doubt.
- Don’t deny your feelings...acknowledge them, face them and deal with them in a positive way as soon as you can.

STEP 4 - TAKE RESPONSIBILITY AND TAKE CONTROL
You must consciously force the metacognitive (beyond consciousness) and the cognitive levels to interact. Do this by consciously thinking about what is in your mind. This allows you literally to
access the psychosomatic (body-mind) network where the memories are stored and redirect it. Start by considering your memories.

**STEP 5 - DREAM ON!**
When dreaming - different parts of your body/mind are exchanging information, and your glial cells are cleaning up your memory networks. On a physiological level, your dream state allows the psychosomatic network to retune itself and get ready for the demands of your waking life.

**STEP 6 - THINK FORGIVENESS**
Forgiveness is a choice - enables you to release all those toxic thoughts. As long as these toxic thoughts dominate your mind, you will not be able to grow new healthy thoughts and memories!!

**STEP 7 - LOVE - TUNE INTO YOUR HEART**
“Research shows that the heart considers and ‘thinks’ about info it receives from the brain. This implies that the heart has opinions of its own. It acts as a still small voice that checks our thoughts for accuracy, integrity and wisdom. This ‘mini-brain’ in the heart literally functions like a conscience.”

**STEP 8 - Touch**
Touch releases endorphins and enkephalins

**STEP 9 - PLAY AND LAUGH**
Play = :) form of stress reduction ~ Laughter = “internal jogging”
Releases “feel-good” chemicals and boosts the immune system. Almost spontaneously, it reduces levels of stress hormones.

**STEP 10 - EXERCISE**
Not so much about cardio fitness ... but more about increased blood flow which nourishes and cleanses the brain and organs. Sweating releases endorphins :) Aerobic exercise helps to sweep away the debris left by toxic thoughts and emotions.

**STEP 11 - DIET**
“Carbohydrates are not optimum foods for thinking ... they anesthetize the mind and dull the thinking process by acting as a blanket that prevents you from listening to all the good news your peptides might be telling you.” !!!
“A diet overloaded with carbohydrates and bad fats (particularly trans fats - the ones that are industrially created as a side effect or partial hydrogenation of plant oils) will tend to add to your body’s toxic load.”
Water is hugely important.

**STEP 12 - THE SPIRITUAL ASPECT**
“You are a spiritual being. No healing of toxic waste in your mind and body will be complete unless you address spirituality.”

**STEP 13 - RELAX!!!**
“ACCELERATION SYNDROME” = hurry sickness. ☺️
Simple Ideas: What to do to Increase Your Positive Thinking...and Decrease Stress Response

~Janet Miller MA LPCC

1. Realize you can decide what you are going to think about. Stop dwelling on negative and dwell on hope... intentionally!

2. Laugh
   a. Increases oxygen to body
   b. Lymph fluids circulated more
   c. Immune system improved
   d. Decreases blood pressure
   e. Improves memory
   f. Average child laughs over 300 x day. Average adult laughs 18-34 times!
   g. Get a CD of a comedian if you need to

2. Dance
   a. This exercise has the biggest impact on improving cognitive skills (not swimming and biking etc.)
   b. Requires rational thinking and emotions to combine = “rewires” cerebral cortex and hippocampus

3. Garden
   a. Repetitive motion
   b. Literally forces you to slow down and “smell the roses”
   c. “Something about digging in the dirt” that is restorative
   d. Research found that people who garden are healthier than people who don’t

4. Spend time with friends who are positive and supportive

5. Creative repetitious motion - Hobby- moves sad pictures from edge of conscious and puts happy pictures back

6. Read something positive daily

7. Journal - especially - writing down what you are thankful for... helps to review your day and notice your attitude and self-talk from the day
8. **Pay attention to body pain** - usually sign of stress, and consider: “What is bothering me that I am having pain?”

9. **Intentionally change your thinking** from worry to faith/trusting things will work out.

10. **Eat nutritiously** - so your brain gets good nutrients. [www.prevention.com](http://www.prevention.com) says that the “mind diet” will decrease the risk of developing Alzheimer’s by 53% =
   a. **Fatty fish** – salmon, tuna, halibut -3x week. These are high in Omega 3 and vitamin D
      (4 oz of Salmon has 600 IU of vitamin D)
   b. **Green Leafy Vegetables** – spinach, kale, collards – 2 servings daily. Vitamin K
   c. **Olive Oil** (get the real stuff = green) – improves learning and memory
   d. **Blueberries and Strawberries** – antioxidant Anthocyanin- cross blood brain barrier and protect the brain from oxidation and increases communication between neurons. 2 or more half cup servings per week. Improves short term memory, navigational skills, balance, and coordination

11. **Regular exercise**
    Besides CV fitness, it releases the build-up of glucose in the muscles and relaxes them, and increases endorphins

12. **Sleep** - at least 7-8 hours a night
   a. Body produces proteins called cytokines which are essential to the immune system when I am asleep
   b. Link between quality sleep and brain function - decision making, cognition, and focus... so if I am tired it will be much more difficult for me to choose to think positively
   c. Turn down thermostat - best sleep is in mid-60 degrees F
   d. No electronic back-lit screens a few hours before bed
   e. Wear socks to bed. Feet are our coldest part of us and if warm we sleep better
   f. Drink plenty of water and decrease or avoid caffeine
   g. Lack of sleep causes weight gain
   h. Consider a 5,000 lux light for 20 min in the first half hour of your morning
   i. A minimal amount of caffeine in the morning decreases REM time and causes us to wake more often that following night!

13. **Play board and card games** - good for relationships and thinking skills
14. Find things that give you pleasure and comfort – (besides mashed potatoes and chocolate) …and do them

15. Think about / notice what you are thinking about and your self-talk and attitudes, and INTENTIONALLY do things so these are positive

16. Say positive things out loud - even if you don’t believe them

17. Listen to positive, hope-filled music – and see #2

18. Work on spirituality - how you do it

19. Memorize something every day
This enlarges the hippocampus so your brain functions a bit younger

20. Pray / Meditate daily – This decreases cortisol!

21. Breathe deeply on purpose
   a. exercise
   b. sitting – do five minutes of 5 second inhalation, 5 second exhalation
Stress

Which are you?
1. **Foot on the gas** – angry, agitated, or “flight” stress response. You’re heated, keyed up, overly emotional, and unable to sit still.
2. **Foot on the brake** – a withdrawn, depressed, or “flight” stress response. You shut down, pull away, space out, and show very little energy or emotion.
3. **Foot on both** – a tense or “freeze” stress response. You become frozen under pressure and can’t do anything. You look paralyzed, but under the surface you’re extremely agitated.

**Things that help us cope with stress:**
- Relationships – support network.
- General outlook on life / attitude / and especially our thoughts.
- Knowledge and preparation you have for the situation you are in.

**For quick stress relief** – go for something that brings comfort… hugging your dog, a favorite piece of gum, the smell a favorite scent, deep breathing, prayer, favorite song, exercise.

Understand the difference between –
  a. **Urgent thing** = tasks based on deadlines.
  b. **Important thing** = do not necessarily have a deadline – they are important because of the impact that they can have on a person’s life.
  c. **Focus on the important things.**

**Signs of stress overload**
1. Upset when things happen unexpectedly?
2. Feel that the important things in your life are out of control?
3. Feel nervous or “stressed” or anxious?
4. Feel you cannot cope with all the things you are supposed to do?
5. Yelled at your dog or a person?
6. Feel irritated at the world?
7. Cried or been way upset for a “little” thing?
8. Frequent headaches – jaw clenching
9. Dry mouth
10. Light headed, dizzy
11. Frequent colds
12. Rashes or itching, or hives
13. Heartburn
14. Indigestion, constipation, diarrhea
15. Frequent heavy sighs, trouble breathing, asthma
16. Chest pain and or panic attacks
17. Frequent urination
18. Diminished sexual desire
19. Appetite changes
20. Sleep issues
21. Difficulty learning new information
22. Forgetful, disorganized, confused, poor concentration
23. Feelings of loneliness or worthlessness
24. Nervous habits, fidgeting, feet tapping
25. Tired, fatigue, weakness
26. Increased smoking, drinking, gambling, eating, habits
27. Hopelessness
28. Hair loss
29. Skin breakouts
30. Heal slower
31. Vision changes
32. “The blues,” moody, boredom, anxiety
33. Increased desire for sweets
34. Women – increased monthly discomfort
Activities to Develop Happiness  by Shawn Achor

1. **Three Acts of Gratitude.** Spend two minutes a day scanning the world for three new things you’re grateful for. And do that for 21 days. The reason why that’s powerful is you’re training your brain to scan the world in a new pattern. You’re scanning for positives, instead of scanning for threats. It’s the fastest way of teaching optimism.

2. **The Doubler.** For two minutes a day, think of one positive experience that’s occurred during the past 24 hours. List each detail you can remember. It works, because the brain can’t tell the difference between visualization and actual experience. So you’ve just doubled the most meaningful experience in your brain. Do it for 21 days, your brain starts connecting the dots for you, then you have this trajectory of meaning running throughout life.

3. **The Fun Fifteen: 15 minutes of cardiovascular exercise a day.** It’s the equivalent of taking an anti-depressant for the first six months, but with a 30% lower relapse rate over the next two years. This is not a repudiation of anti-depressants. It’s an indication that exercise works, because your brain records a victory, and that cascades to the next activity.

4. **Breathe.** Take your hands off their keyboards two minutes a day. And go from multitasking, to simply watching their breath go in and out. This raises accuracy rates. Improves levels of happiness. Drops their stress levels. And it takes two minutes.

5. **Conscious Acts of Kindness.** The final habit is the most powerful that we’ve seen so far. For two minutes each day, start work by writing a two-minute positive e-mail or text praising or thanking one person you know. And do it for a different person each day. Social connection is the greatest predictor of long-term happiness.
Steps in Forgiveness - a perspective by Janet Miller, MA LPCC

1. **Repentance** … “I’m sorry.” (This almost never happens, so the steps that follow are written from the perspective of working at restoration of relationship, and also from the other - of NO relationship restoration, and just my own healing and restoration.)

2. **Forgiveness** … I choose to let go of my “right” to be angry. {It is a heavy burden that makes my life more difficult, and according to research – could even make me physically sick.} This is NOT saying that what happened is okay. This is NOT forgetting what happened!

3. **Reconciliation** … I can be polite to that person but I do NOT trust that person to be safe/not hurt me. If thoughts of that person come up I do not go to that place of anger and hurt and ruminate on it any longer. (This takes practice. 😊)

4. **Testing Time** … I am around that person I have forgiven… I do NOT trust them, but I look to see if that person is doing what they said they would do (like going to counseling or just not being mean to me). Are they working at relationship? Are they continuing to be mean and unsafe or are they making positive strides?

   This might last a few moments or ten years or forever.

   Only at the END of Testing Time – is there trust!!!!

If there has been no “I’m sorry”… then how am I doing with the memory of the hurt? Am I in a place where when I think of that person, anger and hurt are no longer an issue that causes significant emotion and unrest in me? Can I look at that memory and know that I am safe and don’t have to worry about those things anymore?

5. **Restoration** … The relationship is better than it was before the problem. AND/Or – I am restored and moved into a healthy place of emotional and spiritual wholeness… because I have let go of my “right” to be angry and I no longer need to ruminate on that hurt.

**Thoughts to remember** …

Forgiveness is like peeling an onion – it happens in layers and so don’t be surprised if you move through it, and then later, need to do it again as you understand more.

For those of us who are very “justice oriented” – where common words (at least in our childhood) were – “That’s not fair,” giving up my right to be angry is a challenge. What helps me - is to remember that I don’t have to worry about their accountability – I just need to be able to look in the
mirror at a healthy person and not a person loaded down with “rights to be angry”… because I choose to focus on JOY and being well, and not on bitterness.

If there is hurt that is so deep that the above is difficult to do… please find someone, especially a professional, who can listen and help with this process. You will be very glad you did.
Hide and Seek: Where are those Documents?

Have you ever needed a piece of information and just couldn’t find it? It may be even more difficult for the care receiver to focus on finding needed information related to financial and legal affairs, health care matters and after death responsibilities while he or she is ill or dying.

Taking time to find and record this information before it is needed can help you better prepare for those things you may need to do at more difficult times. In addition, it is even more helpful if the care receiver can assist you by explaining the documents/information and helping you locate them.

Look at the items listed on the next page and identify those things that are relevant to you and the care receiver; then find those items and record the information or the location of the information for future reference.

Adapted from the Hospice of the Florida Suncoast – Module 3- SA1 2003
Information and Documents to Put Together

1. Name/s, addresses and phone numbers
2. At least 3 emergency contacts – names and numbers
3. Names of children/others that they would like contacted if ill or death and phone numbers
4. Advanced directives
   a. Living Will
   b. DNR
   c. Health care power of attorney
   d. Financial power of attorney
5. Social Security number
6. Names and numbers of all doctors and what they treat
7. Name and number for preferred pharmacy
8. All meds, dosage, schedule, prescribing doctor, side effects
9. Medical history – past present condition, blood type, drug allergies, surgeries, hospitalizations
10. Health Insurance – policy numbers and contact numbers
    a. Medicare
    b. Medicaid
    c. Private
11. Long-term care insurance – company name, contact name, policy numbers and phone contact number, amounts and if there is a time period you have to pay before they start paying.
12. Legal – estate planning documents – wills, trusts, contact name and number/s
13. Marriage certificate / divorce/separation decrees
14. Adoption papers
15. Organ donor cards
    Contact information of funeral home, and plans they want – (i.e. – songs, people involved etc.)
17. Cemetery deed
18. All computer accounts and Password/PIN for each one
    Retail, banks, social media, email, internet
19. Religion/Faith/Church contact information
20. Neighbors/friends who might be helpful – name/s number/s
21. Employee information – house cleaner, yard care, contact info and prices
22. Automobile titles
23. Deed to house/other property/rental agreements
24. Passports, green cards, visas, citizenship/naturalization papers
25. Name and contact info – financial manager – stock brokers, investments advisors and account numbers, etc.
26. Bank and investment accounts – name of institution, state where opened, account #s, value and associated debit cards etc.
27. Records for and amounts of income – such as insurance payments, SS retirement pension, public benefits, veterans benefits, real estate, support from family
28. Number and location of safe deposit box/es and keys
29. Credit Card companies – account #s, expiration, websites, payment due date, passwords, auto-pay??
30. Mortgage and home equity line of credit documents
31. Expenses – utilities, care, medical, rent, long-term care, home rental, automobile
32. Inventory of valuables – jewelry, art, silver, gold, antiques, vehicles, boats, real estate, and location and current values
33. Tax documents, current receipts and records for deductions
Resources for Caregivers…. Things to Know

1. Write out and find the “list of information and documents”

2. The Area Office on Aging – [www.areaofficeonaging.com](http://www.areaofficeonaging.com)
   - “Older Adults Resource Guide”
     - “Aging” websites
     - Assistance information/resources
     - Home health care
     - Legal paper work help
     - Financial assistance
     - Services for the homebound
     - Housing
     - Education and tours
   - “Caregiving Smarts Resource Guide”
     - Caregiver information
     - Elder law help
     - Resources for care

3. Hospice of Northwest Ohio [www.hospicenwo.org](http://www.hospicenwo.org) 419-661-4001
   - Caring for the Caregiver classes - free
   - Hands-on Caregiving class - free

4. [www.toughquestionsstraightanswers.org](http://www.toughquestionsstraightanswers.org)


6. [www.goldenbuckeye.com](http://www.goldenbuckeye.com)

7. [www.ohioaging.org](http://www.ohioaging.org) Ohio Association of Area Agencies on Aging

8. [www.aarp.org](http://www.aarp.org)

9. [www.asaging.com](http://www.asaging.com) American society on aging

10. [www.aoa.gov](http://www.aoa.gov) - U.S. Admiww.cms.hhs.gov Center for Medicare and Medicaid

11. [www.ncoa.org](http://www.ncoa.org) National Council on Aging

12. [www.nsclc.org](http://www.nsclc.org) national senior citizens law center

13. [www.senior.com](http://www.senior.com)

14. [www.seniornet.org](http://www.seniornet.org) or [ToledoSN@aol.com](mailto:ToledoSN@aol.com)

15. [www.seniorlaw.com](http://www.seniorlaw.com)

16. [www.ssa.gov](http://www.ssa.gov) Social Security Administration
17. [www.alz.org](http://www.alz.org) The Alzheimer’s Assoc
18. [www.careguide.net](http://www.careguide.net) National Child Care Assn (eldercare forum for caregivers)
19. [www.elderweb.com](http://www.elderweb.com) Deals with issues of importance to older adults
20. [www.elderhostel.org](http://www.elderhostel.org) National Elderhostel Office
22. [www.careing.com](http://www.careing.com) Denise Brown’s radio blogs and burnout quiz, etc.
23. [www.agingcare.com](http://www.agingcare.com)
24. [www.drmarion.com](http://www.drmarion.com)
25. [www.caregiver.org](http://www.caregiver.org) National Alliance for Caregiving
26. [www.caringinfo.org](http://www.caringinfo.org)
27. [www.metlife.com](http://www.metlife.com)
28. [www.caregivingclub.com](http://www.caregivingclub.com)
32. [www.caregiving.org](http://www.caregiving.org) National Assoc for caregiving
33. [www.prevention.com](http://www.prevention.com) – health information
Caregiving Apps

Communication and Records – Electronic, iPad, Phone

Care Family
Caring Bridge
Lotsa Helping Hands
MobiCare

www.myfamily.com – create your own

Evernote
Google keep
One Note
Sky Note

Task Apps

Astrid
Errands
Remember the Milk
reQall
Todoist
To odledo
Work flowy

Sharing Apps

Cozi
Green Grocer
Grocery Gadget
Grocery IQ
Shopper
Shopping list
Ziplist

Finances Software
Check
Manilla
Mint

GPS Tracking
Alzheimer’s Association.ComfortZone
eCare +Voice
Lifeline
The mobile Alert system from Medical Guardian
Costco, Sam’s Club, etc. – may sell medical alert systems.
www.eldercare.gov

For Medical Care Records
iBlueButton
Blood Pressure Monitor – Family Lite
Copzule PHR
Glucose Budy
Web MD
Books

1. AARP’s “Juggling Work and Caregiving” by Amy Goyer – free on kindle at Amazon
2. “Giving Care Taking Care – Support for the Helpers” by Sherokee Ilse
3. “Chicken Soup for the Soul – Living with Alzheimer’s and Other Dementias”
4. “A Bitter-Sweet Season – Caring for our Aging Parents and Ourselves” by Jane Gross
5. “The 36 Hour Day” by Nancy Mace and Peter Rabinu
6. “Coping With Your Difficult Older Parent” by Grace Lebow and Barbara Kane
7. “How to Care For Aging Parents” by Virgina Morris

Memoirs about Caring for Someone with Alzheimer’s

1. “The House on Beartown Road: A Memoir of Learning and Forgetting” by Elizabeth Cohen
2. “Elegy for Iris” by John Bayley
4. “My Journey Into Alzheimer’s Disease” by Robert Davis
5. “Circling My Mother” by Mary Gordon
6. “Twilight Travels With Mother: How I Found Strength, Hope, and a Sense of Humor”
7. “Living with Alzheimer’s” by Mary Ann Mayo

Caring for a Spouse with Alzheimer’s

1. “Life With Charlie: Coping With an Alzheimer’s Spouse or Other Dementia Patient and Keeping Your Sanity” by Carol Heckman-Owen
2. “I Still Do: Loving and Living with Alzheimer’s” by Judith Fox
3. “My Spouse Had Alzheimer’s: My Experiences as a Caregiver” by Walter F Heidlage
4. “Jan’s Story: Love Lost to the Long Good-bye of Alzheimer’s” by Barry Petersen
5. “Alive With Alzheimer’s” by Cathy Stein Greenblatt
Early Onset Dementia

1. “Still Alice” by Lisa Genova
2. “Could It Be Dementia? Losing Your Mind Doesn’t Mean Losing Your Soul” by Louise Morse and Roger Hitchings
3. “Alzheimer’s From the Inside Out” by Richard Taylor
4. “Jim’s Journey: The Story of a Young Man with Early-Onset Alzheimer’s” by Gretchen L Dausey

Children’s Books about Alzheimer’s

1. “What’s Happening To Grandpa?” by Maria Shriver
2. “Remember Me” by Margaret Wild
3. “Grandma’s Cobwebs: A Story for Children About Alzheimer’s Disease” by Ann Frantti
4. “Remember, Grandma?” by Laura Langston
5. “Wilfrid Gordon McDonald Partridge” by Mem Fox

Memoirs by Children of People with Dementia

1. “Dementia Diary: A Care Giver’s Journal” by Robert Tell
2. “Minding Our Elders: Caregivers Share Their Personal Stories” by Carol Bradley Bursack
3. “Elder Rage, or Take My Father…. Please! How to Survive Caring for Aging Parents” by Jacqueline Marcell
4. “Mothering Mother: A Daughter’s Humorous and Heartbreaking Memoir” by Carol D. O’Dell

Books by or about Someone with Mild-Stage Dementia

1. “Alzheimer’s From the Inside Out” by Richard Taylor

Books for Young Children Who Have Parents or Grandparents with Dementia

1. “Hugging Grandma: Loving Those With Memory Disorders” by Zina Kramer
2. “Wilfrid Gordon McDonald Partridge” by Mem Fox
3. “Striped Shirts and Flowered Pants: A Story About Alzheimer’s Disease for Young Children” by Barbara Schnurbush
4. “Allie Leans About Alzheimer’s Disease: A Family Story about Love, Patience, and Acceptance” by Kim Gosselin
5. “Still My Grandma” by Veronique Van Den Abeele

Other

1. “One You Love is Dying: 12 Thoughts to Guide you on the Journey” by James Miller
2. “When You Know You’re Dying: 12 Thoughts to Guide You Through the Days Ahead” by James Miller
4. “Gone from my Sight” by Barbara Karnes
5. “When Someone is Very Sick” (children’s coloring book)
6. “Graceful Passages” CDs and book
8. “The Caregiver” by Aaron Alterra
10. “Caring for Yourself While Caring for Your Aging Parents: How to Help, How to Survive” by Berman
11. “When Helping You is Hurting Me: Escaping the Messiah Trap” by Berry
12. “Something to Remember Me By” by Bosak and McGaw
14. “Dying Well” by Ira Byock
15. “Making the Moments Count: Leisure Activities for Caregiving Relationships” by Decker
16. “Caregivers and Personal Assistants: How to Find, Hire and Manage the People Who Help You (or your loved one!)” by Degraff
17. “Caring for Yourself While Caring for Your Aging Parents: How to Help, How to Survive” by Berman
18. “Overwhelmed: How to Work, Love, and Play When NO One Has the Time” by Brigid Schulte
19. “Who Switched Off My Brain” by Dr. Caroline Leaf
20. “Switch On Your Brain: The Key to Peak Happiness, Thinking and Health” by Dr. Caroline Leaf
22. “Twilight Travels with Mother: How I Found Strength, Hope, and a Sense of Humor Living with Alzheimer’s” by Mary Ann Mayo
Basic Fitness

Karvonen Formula:

\[
\text{Your age} \quad \frac{220 - \text{Your age}}{\text{Your resting heart rate}} \times 0.60 \quad \text{(and then do the whole formula again and use .90)}
\]

\[
\text{Your resting heart rate} + \quad \text{Your resting heart rate}
\]

\[
\text{XXX} = \text{your target heart rate training zone at 60% and 90% MHR} \smile
\]

~**~***~***~***~

Warm up – exercise in training zone - cool down

Flexibility work
Blue butterflies and black-eyed Susans
Directed Journaling

1. The person or persons in my life who I am grieving are….

2. Losses that I have had that are related to the above losses. (secondary)

3. Three things that are good in my life right now….

4. Three ways I am coping with my loss/es….

5. If I could be anywhere in the world right now, I would be where?

   And, I would be there with whom? Doing what?
6. My favorite song right now is…. What are the words (as near as I can remember)…..

7. If my internal feelings were described as weather, today I would be what weather?

8. Ten of my most favorite things to eat are…

9. Ten of my most favorite things to do (before this loss if you want) are…..
10. Ten things I miss about the loved one I am grieving.....

11. Three things that I didn’t so much appreciate about the loved one I am grieving. (Just to remind myself that they were human too)

12. Five of my favorite sounds are....

13. Five things that say “I love you” to me.

14. What “thing” best represents the ache and lack in your heart right now and why?
15. One of my most favorite memories of/with the person I am grieving.

16. Something funny the person I am grieving used to say/do.

17. Where was my faith before this loss and where is it now?

18. If I could live anywhere in the world…. It would be…. And in what kind of home?

19. Something I eat that reminds me of the one I am grieving and why.

20. Something I smell that reminds me of the one I am grieving and why.

21. Three things I miss the very most.
22. Three regrets I have about my life and/or my relationship with the one I am grieving.

23. My favorite most comfortable clothes I choose to wear when I need a hug and can be home.

24. Three things I enjoy doing at home when I just want comfort.

25. Two things that were not helpful that someone said to me about grief.

26. One thing that has been really helpful for me – that I read, or someone said, or I discovered.

27. One thing I wish someone would do for me is....and why?
28. What three persons support me in this grief?

29. Two activities that are creative that help me deal with this grief.

30. How much sleep am I getting per night? How much sleep do I need per night?

31. Am I eating a diet full of fruits and vegetables and good protein?

32. The exercise that I get weekly consists of....

33. Three ways I have been dealing with my grief that I would like to improve are...

34. What has been surprising to me in this grieving?
35. What has been the most difficult part of this grieving?

36. Has the idea of being a “strong person” changed since grief started? And how?

37. If I were a color…. Today I would be ____________ and why?

38. One thing I treasure that was given to me by the one I am grieving or that reminds me of them is…..

39. This grief has been ……

40. If someone would be really good at helping me deal with this grief, they would……

41. If I could tell the one I am grieving two things... I would say……
42. How will I know I am healing?

43. What will it be like when I wake up and the first thing I think of does not hurt?

44. Lately after I laugh about something, I feel…….

45. Something that made me laugh the last time was....

46. The last time I cried was.... And why?

47. What was the favorite candy or food of the one I am grieving? When did you eat it last?

48. Three things that I need to let go of are…and why?
49. Three things that the one I am grieving taught/gave me as a person.

50. My favorite season and why?

51. My favorite holiday and how is that / or going to be without the one I am grieving…

52. If I could do anything (job or activity) I would…..
Grief
by Janet Miller  MA LPCC

I never knew missing could be so deep.
   My world has changed…
It seems only a silhouette of its former self - without you in it.

   Yet – I see you in the sunrise
   And I can hear you in the rain…
   I turn to tell you something,
   and realize you’re not here beside me.
   How my heart aches…
   To hear you laugh,
   ….To feel your gentle touch.

   Thank you.
   Thank you – a million thank-yous –
   --For giving me so very much of me.

   I wrap up in a quilt of our memories
   And I sit and wait for this night of grief to pass.

I know you’re in a better place – and I am happy for you….  
But this having to re-learn life without you –
   Well I never pictured it…

   And it seems a great shredding of my soul.
   More than I want to bear.
   It hurts to breathe this night.
   They tell me it will ease…
   And some tomorrow I will laugh and dance again…
   But right now… I need to sit, and be, and hold your memory.

   How I long for you.
   How I will always love you.
   Oh how deep this place of missing is.
There is a space in my heart that is forever yours.
Awareness of Anticipatory Grief

You and the care receiver may begin feeling the effects of loss and grief before a death actually occurs. These are normal reactions to current and future losses. Losses can include those associated with caring for someone with an illness, changes in relationships, and the anticipated loss of a loved one. This anticipatory grief may actually help you prepare for the losses and decrease the intensity of grief after the death occurs.

Causes of Anticipatory Grief

Some of the causes of anticipatory grief are related to fears and actual or possible losses, such as:

- Fears related to life without your loved one.
- Fear of losing your present family structure, such as the head of household, the family matriarch, or frequency of visits from family members.
- Fear of starting over
- Fear of the unknown
- Loss of social life
- Loss of companionship
- Loss of usual eating, sleep, work, and recreational habits
- Loss of independence
- Loss of control, such as being able to care for yourself or a loved one.

Signs and Symptoms of Anticipatory Grief

It is normal to experience combinations of or recurring signs and symptoms of anticipatory grief. Some of the signs and symptoms of anticipatory grief are listed below. As you look through these signs and symptoms, circle the ones you have experienced since you became a caregiver.

- Feelings of guilt
- Tearfulness
- Constant changes in emotions
- Anger
- Depression
- Feelings of emotional numbness
- Anxiety or feelings of fear
- Changes in sleeping and eating habits
- Poor concentration
- Forgetfulness or poor memory
- Loneliness
- Denial
- Acceptance
- Fatigue
What You Can Do

There are things you can do which may be helpful for working through the anticipatory grief process. Some suggestions may include:

- Go for short walks when possible.
- Write in a journal.
- Plan for the future.
- Seek spiritual assistance if needed.
- Talk to someone such as a friend, family member, or clergy.
- Make changes only as needed and put off major decisions when possible.
- Do the things you want to do now. Forget the chores that you can do later.
- Spend time with your loved ones, friends, support group and family.
- Seek help from your family, friends, to arrange some time to spend doing things you enjoy.
- Call your doctor if anticipatory grief feels overwhelming or you want to talk about your feelings.
- Attend a caregiver support group.

Sometimes it may feel that the grief process will not end as you experience loss. If you can work through the pain of the losses as they occur however, the intensity of your grief after the death may be less.

Adapted from the Hospice of the Florida Suncoast – Module 1- SA1/2 2003
Focusing on What is Important

List those things that are important to you and the care receiver at the end of life.

Important to the Care Receiver | Important to You
--- | ---
1. | 1. 
2. | 2. 
3. | 3. 
4. | 4. 
5. | 5. 

Every day for the next week, list the amount of your time you were able to spend on those things that are important to you and the care receiver. Also, identify things that kept you from doing what was important.

<table>
<thead>
<tr>
<th>Day</th>
<th>Time spent on important things</th>
<th>Things that kept me from doing what was important</th>
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<tbody>
<tr>
<td>Monday</td>
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<td>Sunday</td>
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</table>

1. What would you be willing to give up or ask someone else to do so you could spend more time on what is most important to you or the care receiver?
2. Who can you ask for help? What specifically would you ask them to do?
3. What community resources could you use to do some of these things?
4. What could you do differently so you can combine the “need-to-dos” with what is important?

Adapted from the Hospice of the Florida Suncoast – Module 1- SA4 2003
## How Has Caregiving Affected You?

Caregiving affects many aspects of your life. Caregiving can affect your physical health, your ability to care for or take time for yourself, your personal relationships and relationships within the community. Your wellbeing, your sense of how you feel about yourself, and your emotional and spiritual health all affect and are affected by your roles and responsibilities.

Think about how caregiving has affected you, and list those changes below:

<table>
<thead>
<tr>
<th>Changes in my...</th>
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<tbody>
<tr>
<td>Physical Health</td>
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<tr>
<td>Ability to Care for Myself</td>
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<td>Relationships</td>
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<tr>
<td>Wellbeing</td>
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<td>Sense of Spirituality</td>
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<td>Roles and Responsibilities</td>
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Adapted from the Hospice of the Florida Suncoast – Module 1- SA5 2003
How I Feel About…

The experience of caregiving involves many different feelings on a daily basis. These feelings can provide hints you can use to improve your caregiving experience. This exercise can help in different ways by:

1. Providing a new way to privately express emotions so they are not bottled up inside causing additional stress, illness and fatigue.

2. Connecting your feelings and emotions to situations that you may be able to change or improve. (You may find that you are angry each day when you are cooking and cleaning, but by relating the feelings to the tasks you realize it is not really about cooking and cleaning. Instead, it is about not getting help from your family. Or you may feel warm and caring when sitting and reading a favorite novel to your care receiver. Relating the emotion to the situation gives you some choices about how to deal with it and how to spend your time.)

3. Identifying situations that are most important to you or the care receiver.

Through this exercise you may identify issues that are unsettled in your relationship. Examples may be concern about future financial stability or the need to ask for or give forgiveness for a past indiscretion. Once identified, you have the choice to attend to them in a way that is important to you and the care receiver.

Questions to consider after doing this exercise:

1. What feelings surprised you?

2. Were there feelings you did not understand but do now?

3. Were you able to make any different decisions about caregiving after doing this exercise?

4. Have you identified any unfinished issues that you would like to settle before your care receiver is unable to communicate?

Adapted from the Hospice of the Florida Suncoast – Module 1- SA6 2003
How I Feel About...

At the end of the day, take a few minutes to describe the emotions you experienced that day. Be sure to list both positive and negative emotions and what they were about.

<table>
<thead>
<tr>
<th>Date</th>
<th>Today I felt...</th>
<th>About...</th>
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Adapted from the Hospice of the Florida Suncoast – Module 1-SA7 2003
Losses: Past Present and Future

As you experience changes, you will also experience loss. Changes can be uncomfortable, and loss can seem insurmountable. Losses, however, can also be life changing in a positive way. As you experience caregiving, you may lose old perceptions, old beliefs and begin to look at the world in a different way. For example, as the care receiver’s health declines, you may have to give up working outside the home to care for him/her. You experience loss of income and/or career. While caring for your loved one at home, you begin to value that time. You lose your belief that people who stay home to care for someone are not valuable to this world. You gain the belief that caring for a loved one is valuable and by providing care you have a unique ability to make a difference in someone else’s life.

Think about changes or losses you and the care receiver have experienced in the past and are currently experiencing. How have these changes or losses affected you and the care receiver? How would you describe these changes or losses?

<table>
<thead>
<tr>
<th>Losses</th>
<th>How the loss affected or changed your life</th>
<th>How the loss affected the care receiver</th>
<th>Describe the loss as good, bad, devastating, positively life changing</th>
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Future losses: What losses do you anticipate in the future and how will you be affected?

Adapted from the Hospice of the Florida Suncoast – Module 1- SA9/10 2003
**Magic Wand**

Pretend you could get rid of three things by waving your magic wand. What would they be?

1. 
2. 
3. 

List those things you would be willing to give up and/or ask for help doing and name the people who may be willing to help.

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<thead>
<tr>
<th>Willing to give up/ask for help doing</th>
<th>Who could help</th>
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Adapted from the Hospice of the Florida Suncoast – Module 1- SA11 2003
**Wish Upon a Star**

If you could wish away three things, what would they be? You can give away chores, tasks, roles, responsibilities, uncomfortable feelings, physical ailments, conflicts in relationships, behaviors and/or expectations of yourself and others. Write those things inside the star, and make a wish!

Wouldn’t it be great if it were really that easy to just wish away worries, chores, etc.? While you may not be able to just wish them away, identifying what is uncomfortable or time consuming is the first step in actually giving things up. Think about ways to give away the three things you identified. Now think about who could take on the chores or tasks and/or what kind of things would help relieve or take away uncomfortable feeling.

Adapted from the Hospice of the Florida Suncoast – Module 1- SA12 2003
What if... Decisions Near Life’s End

Throughout the experience of caregiving you may be faced with making decisions with and for your care receiver about medical care and treatments. These decisions are not always easy or clear. Near life’s end people are often faced with decisions to accept or not accept care that could affect the quality of life and/or duration of one’s life. Depending on how advanced the illness, and the overall condition of your care receiver, it may be appropriate to either accept treatments or choose not to accept them.

The first step is to know what your care receiver would want. Personal values, beliefs and readiness for life closure all affect choices and decisions. The following questions can be used as a guide to having the conversation with your care receiver so you are aware of their wishes before being faced with these decisions. Keep in mind that there are no right or wrong answers to these questions.

Would you want any care or treatments that prolong your life, but do not add to the quality to your life?

1. If you could no longer eat for yourself…
   - Would you want artificial tube feedings?
   - Under what circumstances would you want tube feedings?
   - Under what circumstances would you NOT want tube feedings?

2. If you could no longer breathe for yourself…
   - Would you want to be put on a respirator (breathing machine) that breathes for you?
   - Under what circumstances would you want to be put on a breathing machine?
   - Under what circumstances would you NOT want to be put on a breathing machine?

3. If your breathing or heart stopped…
   - Under what circumstances would you want CPR?
   - Under what circumstances would you NOT want CPR?

Adapted from the Hospice of the Florida Suncoast – Module 3- SA4 2003
## Community Relationships

In the first column, list any relationships the care receiver had or continues to have in the community. In the second column, list any relationships you have in the community. Include employment, religious affiliations, educational, leadership roles or membership in civic and service organizations or clubs, business relationships.

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<thead>
<tr>
<th>Care receiver</th>
<th>Caregiver</th>
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Circle those relationships that are most important to the care receiver and those that are most important to you.

Think about if there are any of these relationships that the care receiver would like to continue and why. How can these relationships be continued or are there relationships that the care receiver would like to close. How can you help make this happen?

Now, as the caregiver, ask yourself the same questions and consider if some relationships could simply be put on hold until a later time.

Adapted from the Hospice of the Florida Suncoast – Module 4- SA1/2 2003
Personal Relationships

Using the chart below, identify the personal relationships you have with other people (including the care receiver and others such as family members, friends). Write the name of the person in one of the spaces, then write a word on the line connecting that person to you that describes how that relationship makes you feel. For example, you could write the name of the care receiver and the word 'loved' or 'angry he is leaving me' on the line.

Are there other feelings, concerns, conflicts or issues in the above relationships that you would like to address before the care receiver dies?
What words do you think the people you identified on your chart would use to describe their relationships with you?

Now think about those relationships that may need resolution. Prioritize them and determine which issues you are willing to address and which issues you are willing to let go. There will be some issues that will never come to closure, some you choose not to address and some you choose to address but are unable to resolve. The point is that you made a conscious decision about these relationships which may help prevent regrets at a later time.

Adapted from the Hospice of the Florida Suncoast – Module 5- SA1/2 2003
Pass It On

Near the end of life the care receiver often feels a need to pass on to the caregiver, or others, things such as wisdom, advice, a family heirloom or treasure, a family story, a ritual or tradition, life’s lessons learned, a family secret, expectations of you or others in the future, or other things considered important. Passing on these things is part of the closure process for life completion.

List these things below, identifying who is to receive the information or item. Make an effort to spend quiet time with the care receiver in order to have the opportunity to collect intrinsic gifts that are given.

<table>
<thead>
<tr>
<th>Pass it on</th>
<th>To whom</th>
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Adapted from the Hospice of the Florida Suncoast – Module 5- SA6 2003
Conversations That Need to Get Started

For many people talking about death is difficult. Care receivers and caregivers who have had these conversations before the actual time of need are better prepared to help make this time more meaningful and comfortable. The following questions can be used as a guide to help you have conversations about life’s end with your care receiver and to give you information to feel better prepared to assist your care receiver achieve a peaceful death.

Read through the following questions, circling the ones you would like to ask your care receiver. If you feel comfortable, try to start a conversation with your care receiver about the items you have circled.

- Have you thought about what you want your last weeks or days to be like?
- What would you like this time to be like?
- Where would you like to be?
- What would you like to be surrounded by?
- What do you think would make you comfortable at that time?
- Who would you like to be with you?
- Is there anyone you would like to see before the last weeks or days?
- Do you want any specific prayers, rituals, or sacraments to a part of that time? Which ones?
- Who would you like to be a part of those?
- Is there anything you would like to do to prepare for that time?
- Are there any concerns or fears you have?
- Is there anything I can do for you during that time?

Adapted from the Hospice of the Florida Suncoast – Module 5- SA8 2003
Dear Letter Carrier

Sometimes it can be difficult to openly say what you want to say to your care receiver or others. You might be afraid of saying the wrong thing. You might not know how to say those things that are important to you or you might be concerned about what you would feel or how you would act if you said the words out loud. You can reflect on and practice what you would like to say to the care receiver or others, doing so in a private, non-threatening place and in a non-threatening way.

Ask yourself this question: If I knew that my care receiver (or other person) only had a few days to live, what would I say to him or her? Write what you would like to say in a letter. After you have written the letter, you can choose to send the letter, hand deliver the letter, put the letter in a safe place for possible later disclosure, destroy the letter and/or discuss the contents of the letter with the intended recipient. You can also choose to write what you want to say in a journal, diary or even on the back of a napkin.

Adapted from the Hospice of the Florida Suncoast – Module 5- SA9 2003
Greatest Gift

Suppose you could give someone the greatest gift in the world. It wouldn’t cost a penny. It would last forever. What is it that every person was born to want?

What is this gift? Unconditional love. It means loving someone with no expectations of receiving anything – even love – in return.

Why is it the greatest gift? All of us want to be accepted just as we are, to be appreciated, and acknowledged without feeling like someone is trying to change us. How many people have received unconditional love in their lives? How often?

It is a powerful gift to give and receive. The effects can last a lifetime.

It is important to remember that unconditional love has nothing to do with accepting someone’s behavior, which may or may not be pleasant. It chooses only to love the person.

Ways to give unconditional love:

- Look for the good and strengths in the other person.
- Acknowledge them in your mind or out loud with that person. For example, “John, you are so courageous and kind to others.”
- Do not dwell about negatives about the person. We all have our personal set of negatives because we are human! Simply focus on the good.
- Do not expect anything in return, not even a thank you.
- Try to keep positive thoughts about the person in mind whenever you think about them. Practicing can make this a habit and soon it will (almost!) become automatic.

Giving unconditional love can also bring you a gift --- a sense of peace and comfort.

—Janet Bauer, The Michelangelo Effect

Giving another person unconditional love can be challenging, but unconditionally loving yourself can be even more of a challenge as you search for peace and comfort. When you are okay with yourself, it may be easier to find a sense of peace with others.

To practice unconditional love of self, start with positive thinking. Every day, look for the good in yourself and acknowledge the inner strengths that got you through the day. Every night, before you go to bed, acknowledge one thing you did good that day. Even saying, “I was not negative today” is a good thing!
Daily Inspiration

For each day of the week, place a date in the box and write something that inspires you – uplifts you or makes you feel good. The goal is to create a calendar filled with positive, comforting and supportive things to help you through your day. You can choose to write daily, weekly or anytime you find something you like. Items can include a phrase, a word, a favorite quote, a happy thought, the name of someone you love, the name of something that gives you hope, a little sketch, an internet address, a joke, a prayer, a phone number of someone who calms you, a spiritual verse. You can even write a poem across five days if it can sustain you for the week. If you feel doing this activity requires too much time, ask friends to provide the inspirational sayings, etc. or consider sharing this activity with the care receiver. You could also do a month and swap your month with another caregiver. The possibilities are endless.

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Adapted from the Hospice of the Florida Suncoast – Module 6- SA6 2003
**Daily Affirmations**

Take a minute or two at the end of each day to reflect and think about the things that you did and the person you are. In the block for that day, write one thing you did well, one thing you like about yourself or perhaps something you accomplished that you didn’t think you could. Try to make these affirmations positive such as ‘I was patient when a solicitor rang the doorbell and woke up the care receiver.’ Or ‘I am a good companion.’ Or ‘I don’t look that bad without a haircut.’ If you miss a day, don’t worry about it but do try to acknowledge the good things you do every day.

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Adapted from the Hospice of the Florida Suncoast – Module 6- SA3 2003
What I Can do Now

As a caregiver, you invest your time, energy, heart and creativity into helping and nurturing your care receiver. As a caregiver, you also need to nurture your own inner resources in order to continue to provide care.

Complete the following statement with three ways you promise to nurture yourself within the next three months. Your response can include anything that gives you physical or emotional comfort or refreshes your spirit – it simply needs to be something you are going to do for you.

In order to care for myself so that I may enhance the care of others, I will:

1. 

2. 

3. 

Signature

When you have completed your promise to yourself:

• Place this in an envelope.
• Put your name and address on the front of the envelope.
• Seal the envelope.
• Mark the envelope “Open on (a date six months from today)
• Place the envelope in a special place where you can find it in six months.

Adapted from the Hospice of the Florida Suncoast – Module 6- SA8 2003
The Perfect Caregiver

The care needs of someone near the end of life are physically, emotionally and spiritually complex and challenging for one person to do alone or without the support of others. Caregivers sometimes feel guilt due to unrealistic expectations of themselves. They may feel that they could have done more or feel that they did not say or do something for the care receiver that they should have done.

Putting unrealistic expectations on yourself may make the caregiving experience overwhelming as you care for the care receiver and live with feelings of guilt. The following activity is designed to assist you in identifying all you do, all you want to do and the reality of what you can do.

List all of the physical, emotional and spiritual things you do for the care receiver and others.

Describe the “perfect” caregiver.

What does the “perfect” caregiver do that you do not?

Often if you look at the reasons why you are unable to do certain things, you will find that you do not do them for good reasons. You may also realize that the expectations you set for yourself are unrealistic. Remember that perfectionism is relative to the situation. You are doing the best you can do within the experience you share with the care receiver.

Adapted from the Hospice of the Florida Suncoast – Module 6- SA9 2003
Your Job Description

People in the workforce have job descriptions that describe what they are supposed to do for their employer. These might include roles, responsibilities, tasks to be completed and things the person needs to learn to do their job now and in the future. Many employers also slip in something called ‘Duties as assigned’ which means anything that comes up, anything that needs doing that is not usually considered a normal part of the job. Most employees are rewarded with a raise or bonus based on how well they perform the items on the job description.

For example, Nancy Nurse’s job description might state that she needs to care for 12 patients a day, do treatments and give medications to those patients, be a teacher to student nurses, and take classes on medication administration and wound care. If she does this well, she will be rewarded with a dollar an hour raise at the end of the year. She plans to do a good job, get her raise and put that money toward her life dream of traveling around the world.

Think about your caregiving experience. Write a job description that describes everything a caregiver does in a day, a month, a year for a care receiver near the end of life. Include the roles, responsibilities, tasks, things a caregiver needs to learn to do the important work of caregiving and ‘duties as assigned.’ At the end of the job description, include rewards and bonuses the caregiver can receive by providing care for someone near the end of life.

Adapted from the Hospice of the Florida Suncoast – Module 6- SA10 2003
A Caregiver’s Job Description

Roles and Responsibilities:
*include physical, emotional and spiritual tasks

Learning Needs:

Other Duties As Assigned:
*those things that just 'come up,' things others may not even be aware of

Rewards and Bonuses for a Job Well Done:

What do You Plan to do with these Rewards and Bonuses?

Adapted from the Hospice of the Florida Suncoast – Module 6- SA11 2003
Your Support System

Think about your family members, friends, clergy/spiritual advisor and others. Who do you like to be around? Who makes you laugh when you are down? Who is there to hold when you cry? Who do you feel comfortable talking to about your feelings? Who provides you with companionship when you are lonely? Who helps you find peace? Who is available day or night to help you if need it? Who do you trust to walk the dog, feed the cat or clean the fish tank? Who cleans well? Who can cook a good meal? Who makes the best desserts?

The “who” is your personal support system. Your personal support system can be friends, family members, members of your congregation or club, your care receiver or anyone with whom you feel comfortable. It is good to have more than one person as your support system. Think about who currently makes up your support system or those who could become a part of it. And, think about what they do well. In the columns below, write “who” does or could support you by helping you emotionally, spiritually or physically. Then write what that person could do for you.

<table>
<thead>
<tr>
<th>Who</th>
<th>What they can do to support you</th>
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<tbody>
<tr>
<td>Example – my friend Mary</td>
<td>Makes a great apple pie. My favorite comfort food.</td>
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Asking for support from someone may be difficult. Most people really want help, but may not know what they can do for you unless you tell them. Allowing them to help also shows your love for them. To help you feel comfortable asking for help, write a three-sentence “script” for how you might ask for help. You can also practice by saying the words aloud to yourself. Once you are comfortable, ask your support system for help!

Adapted from the Hospice of the Florida Suncoast – Module 6- SA12 2003
I’m Grateful For

As a caregiver for someone near the end of life, you have the unique opportunity to positively affect the care receiver’s end-of-life journey. Acknowledging all you have done is important to see the good that has come from your care in helping the care receiver find peaceful life closure. As you continue to provide care and until the journey ends, write those things you are grateful for – those things you were able to do, say, experience with your care receiver.

For example, you could write:

I’m grateful for being able to keep John at home.

I’m grateful that I was able to talk about death and ease his fears about how I would manage after he is gone.

I’m grateful for:

I’m grateful for:

I’m grateful for:

I’m grateful for:

I’m grateful for:

Be grateful just for being you!

Adapted from the Hospice of the Florida Suncoast – Module 7- SA3 2003
A Balancing Act

There are burdens and there are gains or rewards in the experience of providing care for someone near the end of life. On one side of the scale, write in the burdens that you have experienced as a caregiver. On the other side of the scale, write those intrinsic rewards/gains you have received from providing care to someone near the end of life.

Which side outnumbers the other? Which side weighs more on your mind and in your heart?

Adapted from the Hospice of the Florida Suncoast – Module 8- SA1 2003
Every Day is a Gift

When you care for someone near life’s end, you often gain a new or renewed appreciation of life. You take very little for granted and are aware of the beauty of life, the important things in life – big or small. The purpose of this activity is to give you a way to express your awareness and appreciation of life. Whenever you recognize something of beauty, something of importance, something that gives you joy or peace, write it down. You can make entries whenever you want, whenever you see something in life as a gift to you. It can be something big, something small, something that only you find significant or something significant to everyone.

For example, the crisp bite and taste of a fresh apple in the fall may be something that you consider a gift. A cool breeze on a hot summer day may be a gift. Holding a newborn grandchild may be a gift. A new medication for the prevention or treatment of Alzheimer’s disease may be a gift. Share your appreciation with others if you can, and remember that your ability to recognize a gift is a gift in itself.

Adapted from the Hospice of the Florida Suncoast – Module 8- SA2 2003
What I have Learned

You may have learned many new things as a caregiver. Reflect on what you have learned, which can be simple, profound, or something you would like to pass on to other caregivers. Write your responses after the phrases below. For example:

I learned that…doing things for other people, like bathing and feeding takes longer than doing these things for yourself.

I learned that…keeping the house clean and organized isn’t as big a priority as it used to be.

I learned that…

I learned that…

I learned that…

I learned that…

I learned that…

How can you use what you have learned, now or in the future?

Adapted from the Hospice of the Florida Suncoast – Module 8- SA4 2003
From Now On

Caring for someone near the end of life may give you a unique and new perspective on life. Based on what you have learned from the caregiving experience, about yourself and about life, what would you do differently from now on if you could, and if there was no one to restrict you in any way? Write your response in the column to the left. Next, think about your real life. Which of these could you do from now on, which would have to be modified and how, and which would be impossible? Mark the appropriate column and write in the column how you could or why you could not accomplish these things.

<table>
<thead>
<tr>
<th>What I would do differently</th>
<th>I can do this from now on</th>
<th>I might be able to do this from now on if...</th>
<th>I couldn’t do this because...</th>
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<tr>
<td>Example- quit my job and reconnect with nature by spending my life walking the mountains.</td>
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<td>I only go to the mountains on weekends. I might also be able to reconnect with nature in my backyard.</td>
<td>I need to make a living to support my family.</td>
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</table>

Life will not always be this chaotic, hectic or painful. Try to take what you have learned and what you would like to do, and apply it to your life in the future to make life more meaningful to you. You deserve it!

Adapted from the Hospice of the Florida Suncoast – Module 8- SA5/6 2003
COMMON GRIEF REACTIONS

PHYSICAL
- Breathlessness
- Dry Mouth
- Fatigue
- Over Sensitivity
- Depersonalization
- Muscle Aches
- Motor Agitation
- Motor Retardation
- Appetite Changes
- Shaking
- Headaches
- Stomach Ache
- Heart
- Palpatations
- Sweating
- Choking
- Dizziness

MENTAL
- Confusion
- Preoccupation
- Sense of Presence of the Deceased
- Hallucinations
- Loss of Identity
- Out of Touch with Reality
- Fragmented

SPIRITUAL
- Anger at God
- Emptiness
- Questioning Faith
- Search for Meaning
- Unable to Forgive
- Increased Spirituality

EMOTIONAL
- Anger
- Rage
- Anxiety, Panic
- Guilt
- Helplessness
- Loneliness
- Numbness
- Sadness
- Yearning
- Relief
- Depression
- Abandonment
- Shock
- Disbelief
- Fear of Going
- Crazy
- Ambivalence
- Powerlessness
- Pessimism

BEHAVIORAL
- Searching
- Avoidance
- Crying
- Dreams
- Restlessness
- Disorganized
- Forgetful
- Sleep
- Social
- Withdrawal
- Low Motivation
- Low
- Concentration
- Impulsive
- Regression
- Disturbances
Grief: A Normal Response to Loss

Grief is a normal response to the loss of a loved one. Reactions from grief can affect the whole person. These reactions may include physical, emotional, psychological and behavioral changes. The most important thing for you to remember is that these reactions are a normal response to loss.

Signs and Symptoms of Grief Reactions

As you grieve, you may experience none, some or all of the following grief reactions. Circle the ones that you have experienced during your time as a caregiver or after a death.

Physical

- Weakness
- Tightness in the chest
- Heart palpitations
- Loss of energy
- Loss of sexual desire
- Upset stomach
- Feelings of exhaustion
- Restlessness

Emotional

- Sadness
- Anxiety
- Fear
- Anger
- Guilt
- Despair
- Feelings of helplessness
- Loneliness
- Feelings of emptiness
- Feeling numb
- Loss of ability to feel pleasure
Psychological

- Feelings of confusion
- A sense of unreality
- Difficulty concentrating
- Preoccupation with thoughts of your loved ones
- Dreams of your loved one
- A sense of presence of your loved one

Behavioral

- Angry outbursts
- Impatience
- Agitation
- Withdrawal from relatives and friends
- Social isolation
- Getting up at night
- Pacing
- Talking constantly about your loved one
- Avoiding conversation about your loved one

If these reactions occur over long periods of time, intensify or begin to interfere with your physical and emotional wellbeing, you may want to talk to someone you trust such as another family member, friend, clergy/spiritual adviser or counselor. You may also want to attend a bereavement support group or consult a healthcare professional specially trained to help with grief.

Remember: Grief reactions are expected and normal.

Adapted from the Hospice of the Florida Suncoast – Module 9- SA1/2 2003
Personal Loss History

The purpose of this activity is to help you acknowledge past losses and identify any factors that may help or hinder your grief process. Think about and respond to the following questions. You may then want to identify any issues or feelings related to these losses that feel uncomfortable or possibly unresolved and discuss these feelings with someone you trust such as a friend, family member, clergy/spiritual adviser or counselor.

1. The first death I can remember is:

2. I was (age):

3. The feelings I remember I had at the time:

4. The first funeral (wake or ritual service) I ever attended was for:

5. I was (age):

6. The thing I most remember about that experience is:

7. My most recent loss was (person, time, circumstances):

8. I cope with this loss by:

9. The most difficult death for me was the death of:

10. It was difficult because:

11. Of the important people in my life who are now living, the most difficult death for me will be the death of:

12. It will be the most difficult because:

13. My primary style of coping with loss is:

14. I know my own grief is resolved when:

Adapted from the Hospice of the Florida Suncoast – Module 9- SA3 2003
I Am

The purpose of this activity is to help you redefine the personal and social side of yourself. This activity may be challenging to you if you have been a caregiver for a long or intense period of time or if you have been with the deceased for so many years that you see yourself as a part of him/her. This is normal and a tribute to your care and commitment. This activity may help you think about other roles you would like to take on, identify characteristics that have emerged during your experience as a caregiver, new interests you would like to pursue and new things you would like to learn.

Write the ten words that describe your characteristics and qualities.

1. 
2. 
3. 
4. 
5. 
6. 
7. 
8. 
9. 
10.

Write five words that describe your favorite activities or hobbies.

1. 
2. 
3. 
4. 
5.

Write two things you feel you need to learn to do that you have never done. These can be tasks or behaviors like cooking, balancing a check book, finding humor in life, etc. (or things your loved one used to do for you).

1. 
2.

Adapted from the Hospice of the Florida Suncoast – Module 9- SA6 2003