

Caregivers of Patients at the End of Life

Adapted from Glajchen, M., Protenoy, R.K., Fraidin, L., & Goelitz, A. A Caregiver Resource Directory: A Practical Guide for Family Caregivers, 2nd edition. New York: Beth Israel Medical Center, 2001.

I. Self Care Checklist

While caring for your loved one, it is important not to forget about yourself. Try to make sure that you are attending to your emotional, social, physical and spiritual needs by

Emotional

- ⑨ watching out for signs of emotional distress, such as depression and anxiety
- ⑨ properly managing symptoms of emotional distress such as depression, anxiety, anger, and stress
- ⑨ seeking professional help when unable to cope with emotional distress
- ⑨ talking with close friends or family about your feelings, or any changes in your mood that they have noticed

Express Your Feelings By:

- . • identifying what is it that you are feeling and allow yourself to accept the emotions as a natural response to caregiving
- . • Avoid bottling up your feelings.
- . • Share what you are feeling with the patient, if you feel it's appropriate.
- . • Call a close friend or family member with whom you can discuss your feelings.
- . • Write down your thoughts and feelings in a private journal.
- . • Join a local support group for caregivers or families of ill patients.
- . • Get a referral to speak to a professional therapist who can help you understand and deal with your emotions.
- . • Speak to a chaplain, priest, minister, rabbi, or other religious figure.

Here are some feelings that caregivers commonly experience. You may experience one or all of these feelings regularly or intermittently. The chart provides you with some suggestions on managing the distress you may experience as a result of these feelings.

FEELING

Anxiety – Descriptors

Worrying a lot

Feeling stressed, edgy or overwhelmed

Have repetitive thoughts

Having tense muscles

Feeling that something terrible is going to happen

Ruminating about little things

Feeling short of breath

Tips for Coping with Anxiety

Prepare yourself as a caregiver by reading about care giving in books or on the Internet.

Make a list of all the things you are worried about and then try to come up with what you can do to reduce your anxiety about each concern.

Learn about your loved one's illness by talking to the doctor, reading books or patient materials about the disease and using the Internet.

Talk to other caregivers who are in a similar situation by joining a support group, joining chat rooms on the Internet or linking up with other caregivers through advocacy groups

Watch a funny movie or television show, read a comic or do something else that will help make you laugh.

Distract yourself from anxious thoughts by using guided imagery.

Do some exercises. Doing physical activity can help relieve tension and clear your mind.

Take some slow, deep breaths and practice a relaxation exercise.

Try to put worries into perspective

Consider whether it would be best to seek to seek professional help.

Sadness/Depression - Descriptors

Feeling down in the dumps	Poor appetite and significant weight loss
Frequent crying and tearfulness	Sleeping too much or too little
Loss of motivation or energy	Feeling worthless
Inability to think or concentrate	Thinking about death or suicide
Increased appetite and significant weight gain	
Loss of interest or pleasure in usual activities	

Tips for Coping with Sadness and Depression

One of the best ways to ease depression is to get out and get your attention on something else.

Though it may be hard to do, you will be surprised how helpful making plans and getting out of the house can be.

Talk about your feelings to a close friend or family member, mental health professional, or support group.

Try to make some positive changes in your life, which will make you feel better.

Exercise. The natural chemicals that get released when you exercise can give you an emotional boost.

Consider whether it would be best to seek professional help.

Anger/Frustration - Descriptors

Feeling easily annoyed	Feeling irritable
Feeling powerless to change the situation	Feeling helpless
Feeling like you want to give up	Displaying irrational behavior
Getting mad about little annoyances	Throwing or hitting objects
Acting aggressively toward others	Feeling hostile toward others
Feeling like your loved one or the situation is not living up to your expectations	
Experiencing increased heart beat/pulse and breathing, or clenching jaws when confronting irritating incidents	

Tips for Coping with Anger and Frustration –

Don't let anger bottle up. Express your feelings in a calm constructive way as you experience them.

Question whether you are justified in being angry. Consider the evidence and determine if you have a valid reason to be angry.

Think about whether getting angry will make a difference in the situation.

Consider your expectations of the other party or the situation to see if they are realistic. If not, try to change your expectations so that you will not be so easily angered or disappointed.

Use "I feel..." language when expressing feelings to others rather than placing blame or accusing them. For example, instead of saying, "you never help me around the house," you might say, "I feel upset because I think that I am not getting the help I need around the house." –

Distract yourself from angry thoughts by using thought imagery or visualization.

Calm yourself down with relaxed breathing and other relaxation techniques.

It does not do you any good to hold onto angry feelings. Let go of your anger and move on by forgiving the person with whom you are angry.

Talk to an objective, uninvolved party about your feelings to vent and get another perspective. –

Laugh...think about something funny when you feel your anger getting out of control. It is difficult to feel angry when you are laughing.

Try to focus on the present situation and don't let old anger and pain get confused with your feelings about the present situation.

Grief – Descriptors

Experiencing emotional pain associated with the loss of anything that is an important part of your life.

Feeling sad about changes in the person you love, and/or in your relationship with him/her.

Being disappointed about lost hopes, dreams, and plans for the future.

Feeling upset about changes in your social life, and relationships with friends and family members

Feeling disappointed about changes in your work/professional life and in your career goals.

Tips for Coping with Grief

Allow yourself to grieve for changes in your life and plans for the future.

Try to focus on the positive things in your life, rather than the things that you have lost

Do not isolate yourself from family and friends who care about you.

Know that feelings of grief and loss are normal and that, given time, the acute pain will subside.

Express your feelings to the patient or others close to you.

Take control of the situation by transforming your expectations for the future.

Make a new plan for the future based on the positive things that you have in your life.

Talk to a mental health professional or join a support group.

Guilt – Descriptors

Feeling like you have done something wrong

Feeling like you are not doing enough for the patient

Feeling like you should not enjoy yourself because the patient is unable to

Feeling bad about thoughts and feelings you are having

Having regrets about relationship problems you have with the patient now and in the past

Feeling like you could have done something to prevent the patient's illness

Feeling like you should not be the healthy one.

Feeling like you have neglected other family members and friends due to care giving

Tips for Coping with Guilt

Guilt can come from feeling bad about thinking “unacceptable” thoughts. For example, a common distressing thought is wishing the patient would die to end his/her suffering.

Try not to let yourself feel guilty about thinking such things. Let these thoughts pass without dwelling on them too much or beating yourself up about it.

Express guilty thoughts and feelings to a friend, support group, or mental health professional. Chances are, it will help you recognize that your guilty feelings are natural reactions to the situation.

If you have done something to feel guilty about, try to talk to the patient and seek their forgiveness. You will feel much better if you clear your conscience

Try to let go of your guilt and accept that you are doing the best you can under the circumstances

Making Time for Yourself

Everyone gets stressed out and needs a break sometimes – most of all, caregivers. It is difficult to confront all of the feelings that you are having when you are constantly with the patient. It is vital for you to take some time away so that you do not become overwhelmed by the stress that care giving can bring. Even short breaks can restore and renew your emotional energy. However, taking breaks requires planning so that you can feel secure and comfortable during your time away from the patient. You can begin by arranging for alternate care for the patient for a short amount of time. Do something that you enjoy and let yourself and the patient become comfortable with the idea of your absence. As you both become more comfortable, you can begin to increase the length of your outside activities.

Tips for Planning for Yourself

Don't feel guilty about wanting or needing time away from the patient or from your duties as a caregiver.

Know that it is okay and necessary for you to have some time for yourself.

Make a list of people whom you trust to care for or stay with the patient during your absence. Then ask someone.

If you don't have anyone in your social circle, you can obtain a volunteer or hire someone for a short time. You may be able to locate such people through local agencies, churches, or synagogues.

Start off slowly, by making plans to spend a short time away from the patient.

Don't let the patient make you feel bad about leaving. Having some time apart can empower both you and the patient, making you each feel a little more independent.

Remember that as long as the patient has proper supervision, your absence will not put the patient at risk.

Try to enjoy yourself and not worry too much too much while you are away.
Allow yourself time to focus on you

Social Needs

- ⊙ Visiting or talking with close friends and family
- ⊙ Doing something you enjoy
- ⊙ Maintaining other activities that are important to you, such as work, hobbies, etc.
- ⊙ Trying to get out of the house at least once a day
- ⊙ Taking a break from care giving at least once a week

Power of Social Support

Caregivers can begin to feel socially isolated if they do not have the opportunity to visit or go out with family and friends as they have before they became caregivers. Social support and the love of family and friends helps you feel less alone and feel able to cope with the challenges of care giving. Let family and friends know that even though your daily focus has changed you remain interested in their lives and concerns and offer support to them. Suggest ways that you can remain connected and close especially if you cannot get out as you used to.

Some Ways to Maintain Social Relationships

Reassure friends and family that although you may be busy, you do need and appreciate their support

Be open and share your experiences as a caregiver with your friends and family so that they can try to understand what it is like for you

Explain the patient's diagnosis with those who are not familiar with it

Invite friends and family over to visit or help while you are caring for the patient

Take time to call and catch up with those friends and relatives with whom you have lost touch. Be sure to ask them about their lives rather than just talking about your situation. This can serve as a great form of distraction.

Maintaining Your Own Life

It is not healthy to spend all of your time with the patient, which can lead to resentment of him/her if you don't feel like you are able to live your own life. Just as it was normal for you to do things without your loved one before he/she was ill, it is okay now. You are an individual with your own interests, thoughts and desires. At least some of these interests, thoughts, and desires need to be expressed and fulfilled so that care giving does not consume your life. Though work can sometimes be an additional burden, it is a good

way for you to maintain a sense of purpose outside of care giving. If you are retired or unable to hold a job because of your care giving responsibilities, there are plenty of other things you can try.

Tips For Maintaining Your Own Life

Don't feel guilty about asking or hiring someone else to take care of the patient while you do something on your own.

If you don't work, look into jobs that would allow you to work from home.

Accept invitations to social gatherings.

Find a hobby or activity that you like and do a little every day.

Do something once a week that you enjoy.

Tips For Leisure Activity

Plan an enjoyable activity to which you look forward at least once a week.

Remind yourself that getting out does not mean that you are abandoning your loved one.

Get a beeper or cell phone so you can check on your loved one or be reached in an emergency.

If you cannot get away from the house, invite a friend to spend some time with you at home.

Physical Needs

- ⊙ Eating at least three meals per day
- ⊙ Eating healthy, well-balanced meals
- ⊙ Drinking enough water every day
- ⊙ Cutting down on fatty foods, sugar, caffeine, and alcoholic beverages
- ⊙ Getting an average of six to eight hours of uninterrupted sleep per night
- ⊙ Exercising for at least 20 minutes, two to three times per week
- ⊙ Taking time to relax daily
- ⊙ Seeing your own doctor and dentist according to schedule

Spiritual Needs

Spirituality means different things to different people. It may include faith or whatever provides a sense of personal meaning in life (and death). Spiritual health can be sought through formal religion, prayer not associated with any religion, meditation, soul searching and social ties with family, friends and others. When dealing with illness, spiritual issues often come to the forefront of the patient's life, as well as your own. Illness and other adversity disrupt your sense of meaning, your values and even your faith. Addressing your own spiritual needs can help you deal with these concerns and

open the possibility of growth from your situation. In doing so, you may be better able to accept your situation, and even find some positive aspects in your role as caregiver. It is not unusual in dealing with the illness of a loved one to wonder why this is happening to them and you. In your search for understanding, you may find yourself asking and wanting to know

“Why”,

“Why has GOD done this to someone I love...”,

“Why am I being punished like this?...”,

“What do we do to deserve this” ...

Often there is no logical reason or logical explanation. With support and reflection, you may be able to move onto “Why not us” and cope with your situation.

Take time out to pray, meditate, or practice spiritual rituals to nurture yourself.

Speak to a chaplain or religious figure who has experience working with health problems. They may be able to help you cope with your feelings and situation.

Explore your beliefs and try to use them to support you in your situation.

Reconnect or establish a connection with a religious community or group. Even when you experience doubt or have lost faith, this can be a great source of comfort.

Try to find meaning in your role as a caregiver and the positives it brings to your life.

Talk to others in similar situations and see how they have integrated spirituality into their care giving.

Think about what you have learned from your situation and how you can help others in their struggle.

Stress Reduction

Stress is defined as a combination of emotional, physical, and behavioral responses to threatening or challenging circumstances. Stressors, the sources that cause stress, include the small hassles of daily life, as well as major life events and tragedies. Being a family caregiver can be extremely stressful. The overwhelming physical demand, the daily responsibilities to which you must attend, and the emotions you feel about your loved one's illness and being a care giver can lead to tremendous stress. Living with **CHRONIC** stress of this type can increase your risk for physical as well as psychological problems.

It is important to learn to recognize and control your stress to prevent problems. Stress management tools will help you reduce the tension associated with difficult feelings and situations.

Begin by:

Determining the major sources of stress

Think about ways that you might be able to change or reduce stressful triggers.

Recognizing when you are under stress.

Deciding whether you can learn to manage stress on your own, or whether you need professional help.

Learning, practicing, and using stress reduction techniques.

Techniques:

- **TIME OUT**

Take time to do something you enjoy and get your mind off your worries. Try reading, listening to music, watching a movie, spending time with a friend, or taking a warm bath.

- **EXERCISE**

Find a form of exercise you enjoy, which could include yoga, swimming or taking a walk. You should always check with your doctor before starting any type of strenuous exercise program.

- **BE ASSERTIVE Don't say "yes"** when you really mean "no." Do not passively accept something that seems unfair or makes you uncomfortable. Learning to be assertive can teach you to stand up for your rights, without bullying others or letting them intimidate you. You can learn how to be assertive through self-help books or by seeking professional help from a psychologist or therapist who specializes in cognitive-behavioral therapy.

- **THINK POSITIVE**

Try to stop negative thinking and refocus your attention on more positive thoughts. Rethinking can help you identify and monitor negative, unproductive thoughts, challenge these thoughts, and replace them with more realistic ones. You can learn how

to change your thoughts from a therapist or through self help books.

- **MANAGE YOUR TIME**

Make the most of your time by establishing priorities that highlight your most important goals; making realistic schedules, eliminating unimportant tasks from your schedule and learning to make decisions that will maximize your time.

- **RELAX**

Take some time to let your mind and body relax. Learn techniques such as deep breathing, visualization/imagery, muscle relaxation, mediation and self-hypnosis for relaxation.

Relaxation Exercises: These exercises are useful techniques to help relieve tension, decrease worry, improve sleep and make you feel generally more at ease. These exercises use physical and mental activities, which focus attention on calming the body and mind, creating feelings of comfort. Review the exercises described below and select one that is comfortable for you. You can concentrate on mastering one technique or use several of the techniques to vary your routine.

Relaxed breathing

- Find a comfortable place and lie down on your back or sit in a chair.
- Breathe in through your nose slowly, in a natural, gentle way.
- At the same time that you take in each breath, gently expand your belly to fill with air. Keep your shoulders and chest as still as possible. Imagine that you are filling a small balloon inside your belly with air each time you inhale.
- Breathe out through your mouth, emptying your belly and letting it relax. As you breathe out, purse your lips to create a little resistance to the exhale to keep it slow, like gently blowing on a candle to make it flicker. Breathe out as slowly as you can, making each exhale last.
- When you finish your exhale, wait quietly until your body naturally take its next breath. Take your time.
- Each time you breathe in, imagine a balloon filling with air, and each time you breathe out, imagine a balloon deflating.
- Be sure to breathe in a slow, gentle, and natural way. If you become dizzy or light-headed, take smaller breaths and slow down.
- It may help to put one hand on your stomach (over your belly button) and one hand on your breastbone. Watch to see which hand is moving more when you breathe in and out. Try to get the hand on your stomach to move more as you breathe, without forcing it.

Begin to practice frequently for short periods of time. Maybe 10-15 times per day for one to two minutes each time. Try to practice in different situations, such as lying down, sitting, standing, or waiting in line.

Muscle relaxation

- Begin by getting into a comfortable position and closing your eyes. Use some relaxed breathing to calm yourself. Take about four slow, deep breaths.
- Relax your whole face. Start with your jaw and tongue. Are you clenching your jaw? Are you pressing with your tongue? Let all the muscles of your jaw and tongue relax. Allow your teeth to be slightly parted in a natural, unforced way. Your tongue should be loose inside your mouth, resting against the back of your teeth. Next, pay attention to your eyes and forehead. Make sure that you are not squeezing your eyes shut or furrowing your eyebrows. Let your eyes close so that your eyelids barely touch. Your whole face is completely relaxed.

- Now, relax your shoulders. Let go of all of the tension in your shoulders and let them drop. Let any feelings of tension in your neck flow away. Let your shoulders and neck muscles sink into a pleasant state of comfortable relaxation.
- Relax your arms, hands, and fingers. Are you feeling a muscle? Are you gripping anything with your hands? Let your arms feel heavy and relaxed, like a floppy rag doll.
- Let any feelings of tension in your back, chest or abdomen dissolve and flow away. Let yourself become more and more limp and relaxed with every breath you take.
- Relax your legs, feet and toes. Let go of any tension from your legs. Let your leg muscles sink into a deeper and deeper state of pleasant comfort. Make sure you are not pressing your feet or toes. Let your feet and toes become completely relaxed.

For the next moment or so, let your entire body become more and more relaxed. Enjoy this feeling of comfort and relaxation, and when you are ready, open your eyes slowly and remain quiet for another moment or two.

Imagery/Visualization

- To begin, lie down, get comfortable and close your eyes. Use some relaxed breathing to calm yourself. Take about four slow, deep breaths.
- Now, picture yourself in a quiet, special place. A place that is very beautiful and feels peaceful and safe. You are all by yourself and feel totally relaxed, safe and at peace in this quiet, special place. It can be a place in nature, such as a beach ... a lake ... a forest ... a field ... a mountain ... a church ... a favorite room ... somewhere you have been in the past.
- Picture yourself in this quiet, special place as vividly as your can, using all of your senses. Look around. Notice what you see. The colors ... shapes ... what the light is like. Perhaps the blue of the sky, or the reflection of the light upon the water. Notice what you see in your special place.
- Notice the sounds, what you hear. Perhaps the lapping of water against the shore, or the sound of wind rustling in the leaves. Listen to the sounds in your quiet, special place.
- Notice the smells in the air. Perhaps the smell of the salt water...or the fresh clean smell of country air...or the smell of pine needles in the forest. Notice the smells.
- Feel how warm, or cool the air is against your skin. And picture where you are. Are you lying down? ...sitting?...leaning against something?...standing? Use all of your senses to make this special place as vivid and real as you can. Memorize the smells, sounds, and sights. Continue to enjoy being in your special place for a minute or two longer. Allow yourself to relax even more deeply. Remind yourself that you can come back and relax here whenever you want. When you are ready, open your eyes slowly and continue to remain still and enjoy your relaxation for another moment or two.

Meditation

- Sit comfortably in a chair with your legs apart and your hands in your lap.
- Keep your back straight and keep your head up with your chin tucked in slightly.
- Close your mouth and breathe through your nose. Position your tongue softly on the roof of your mouth.
- Close your eyes or focus on a spot on the floor about 4 feet away.
- Take deep abdominal breaths, but do not force them. As you breathe, focus completely on your breathing. Pay attention to the feelings of the inhale, the point at which you stop inhaling, the pause between inhaling and exhaling, and the exhale.
- As you exhale, say “one” to yourself. Continue counting each time you exhale by saying “two...three...four.” Then begin again with “one”. If you lose count, start over with “one” again.
- When you notice that your mind has wandered, note this, then gently return to counting your breathing.
- If a particular sensation in your body catches your attention, focus on the sensation until it goes away. Then return your attention to breathing and counting your breaths.
- When you first begin to practice, maintain the meditation only for as long as is comfortable, even if this is only for 5 minutes per day. As you practice and meditation becomes easier, you will find yourself wanting to extend your time. In terms of relaxation, 20-30 minutes once or twice a day is adequate.

There are local classes, resources in bookstores, and on the Internet to help you progress in all of these techniques. Some suggested sites are:

<http://www.healthjourneys.com> and <http://www.amazon.com/audio>.

II. Balancing Caregiving and Ongoing Responsibilities

As we have noted, caregiving at the end of life affects your own physical, social and emotional health. We know that the demands can also interfere with your performance at work, your relationship with your partner and/or the care of your children. It is important to recognize stressors early, address conflicts directly and develop a plan to provide relief.

Work

It can be nearly impossible to keep doctor’s appointments, provide home care and meet unexpected crises while maintaining your normal routine. You may need to focus on maintaining your job due to need for salary, medical benefits or because it is important to your overall well-being.

- Talk with your supervisor, there may be ways that you can adjust your work hours, work from home or lessen hours for a designated time period. Job sharing may be an option for you and another part-time employee.
- Many employers want to keep their experienced, valued employees and will try to work with you. Remember that when you are at work to concentrate on work.
- There may be family members, friends or neighbors who could stay with the

- patient for a few hours as needed. They often are waiting for you to ask.
- Check your home care options. Your insurance may cover some home care benefits. There are also reputable private providers. Your local Ombudsman or Agency on Aging can provide you with a list.
 - Explore the details of your sick leave and other PAID TIME OFF benefits. You may be able to use your sick leave to care for family members.
 - The Family and Medical Leave Act (FMLA) protects the jobs of workers in companies with 50 or more employees. It entitles employees to 12 weeks of annual unpaid leave in order to care for family members. This leave can be taken in blocks of time, or days at a time. Though workers may not be paid during this time, they continue to receive medical and other benefits, and are assured that their jobs will be there when they return. You can learn more about the FMLA at **1-800-959-FMLA** or at <http://www.dol.gov/dol/esa/fmla.htm>.
 - If you are on leave, call your employer and keep them informed on how things are going for you. They are concerned and may have some other suggestions to help you.
 - Remember to tailor whatever you do to what your family needs. You may well not be able to manage the stress of care giving and working. Identify priorities and know that you may have to make some difficult choices.

More Information: <http://www.cancerandcareers.org/coworkers>

Family

The stress and time involved in care giving can take a toll on your relationships with family members. You may find that you have less time to spend with you healthy loved ones, less energy to play with your children, less intimacy with your spouse, and less patience with siblings. This can lead to tension, misunderstandings and conflict. You may experience a shift in responsibilities in the family that can disrupt usual relationship patterns. You may be making decisions or carrying duties that the patient used to do.

Here are some ways to work on continuing positive relationships.

WITH YOUR SPOUSE OR PARTNER

- Talk openly about your concerns and emotions.
- Try not to take your frustrations out on your partner.
- Make sure to tell them you miss them when you are apart more than usual.

Make the most of your time together.

- Ask your partner for help or advice, don't shut them out.
- Tell you partner how you feel about them and show them.
- Schedule special times for the two of you when possible.
- Seek professional counseling if you are not communicating effectively, for example, frequent arguments over "nothing."
- Pay attention to the intimate aspects of your relationships. Talk about your exhaustion, sadness, or stress that may be affecting your relationship.

- Ask them about themselves and how they are feeling.

WITH YOUR CHILDREN

- Try to prepare them for what may come. Listen to their questions and clarify what they are asking for before giving them “adult” answers.
- Talk with your children about the situation; give them a clear picture without overwhelming them with too much information and unnecessary details.
- If children are going to visit the patient, describe how the patient will look, details re equipment, etc.
- Involve children by telling them how they can help out. Suggest they make cards, place phone calls, make treats, or help with household chores and tasks.
- Try to keep children’s routine as normal as possible. If there are changes, put them into the routine.
- Make special times to be with children.
- Pay attention to their behavior. If they are acting different, this may be a sign that they need attention. Children may not be able to put into words what they are feeling.
- Show them they are loved. Shower them with affection and praise. Acknowledge how they are feeling.
- Help them understand that they are not responsible for your physical and emotional distress caring for your loved one. They need reassurance often.

WITH YOUR SIBLINGS, EXTENDED FAMILY MEMBERS, AND STEP RELATIONS

- Recognize the emotional impact will vary even among siblings. Avoid judgmental statements. Offer gentle understanding and forgive thoughtlessness.
- Share responsibilities. A sibling who cannot provide physical care may be able to manage bill paying, cleaning, or other duties.
- Ask for specific help. Describe what you need.
- Keep the lines of communication open especially with those out of town. Update them regularly. You can set up communication trees with voice mails and e-mails.
- Involve them in ongoing decisions on goals of care and changes in patient’s status.
- Talk about concerns before they turn into resentments. Not all siblings are on the same wavelength.
- Include other relatives and friends of the patients if they have had a close relationship with you and the patient.
- Seek counseling to manage your anger, resentment, jealousy, and other emotions. This will help you communicate with your siblings in a loving, concerned manner.

WITH YOUR IN-LAWS:

- . • Keep focus on patient's needs
- . • Let them know how they can help. They cannot read your mind.
- . • In stressful and frightening situations, people may not behave as you expect. Give them information and time to accept changes.
- . • Talk to them about patient's expressed preferences for care so there will be no misunderstanding as death approaches.
- . • Respect their point of view, but respect patient's needs first.
- . • Avoid the "if only", "you should have" discussions. Focus on current situation. This is not the time to work out old resentments.
- . • Try to forgive when feelings are hurt and move on.
- . • No matter how you feel about them, they are family. Respect those ties.
- . • Seek support elsewhere as needed.

III. Advance Directives and Advance Care Planning

Introduction In 1990, Congress passed the Patient Self-Determination Act. It requires health care institutions to tell patients and the people in their communities about their rights under Virginia Law to make decisions about their medical care. These rights include the right to make oral or written declarations – **Advance Directives** – about their care.

Advance Directives Sections You do not have to fill out all the three sections of an Advance Directive to make the document valid. The sections are as follows:

Durable Power of Attorney for Health Care Decisions (DPOA) – You may designate a DPOA to make health care decisions for you if you are unable to participate in decision making due to mental or physical disability. The DPOA is only in effect during that time. The DPOA can be granted a range of powers (See form for list). You may cross out any power you do not want to grant the DPOA. It is critical that you inform the person you designate that: 1) you have appointed them; 2) they agree to serve; and 3) share with them your preferences.

Healthcare Instructions – You may list what treatments and interventions you would like to receive if you are unable to participate in making decisions. This provides your DPOA and care providers with instructions on what to do for you.

End of Life Instructions – The End of Life instructions go into effect only if you are unable to participate in decision making and are in a terminal condition. A terminal condition is defined as one that is incurable and will result in death in six months. It also includes a permanent vegetative state even if death is not imminent. You may state what your preferences are for care at the end of life including foregoing aggressive treatments and receiving adequate pain control

Organ Donation – You may document your wishes to donate organs, tissue or your

body after your death. Your physician and DPOA are obligated to follow your wishes.

IMPORTANT POINTS

- Advance Directives do not require attorney preparation but you may want to obtain legal counsel if you have questions or complex requests.
- The Advance Directive must be signed by two witnesses. The witnesses may be related to you or designated as your DPOA. However, it is recommended that your DPOA not serve as a witness to avoid any concern about conflict of interest.
- The Advance Directive does not need to be notarized.
- Make copies of the document to bring with you at every hospital admission, to give to all your physicians, your DPOA, and family members.
- Review the document on a regular basis to ensure that it reflects your current thinking.
- The document must be honored by all your health care providers.

To print a copy of the Virginia Advance Directive Form,
go to <http://www.inova.org/patient-and-visitor-information/making-healthcare--decisions/index.jsp>

WEB RESOURCES:

Aging with Dignity: Site of Five Wishes* document. This is a more expansive form that helps you express your wishes in a variety of situations.
<http://agingwithdignity.org>

Midwest Bioethics Center: Site of Caring Conversations workshop. The workbook outlines a process to help you facilitate conversations about Advance Directives and advance care planning with your loved ones. You can download it from the site.
<http://www.midbio.org/workbook.pdf>

Other Helpful Documents and Information:

If you gather the documents and information listed below, you will have them available for ready reference as needed.

1. Records of all the medications the patient is taking and the names of the physicians who ordered them. You should also note any reactions that the patient has had to the medication for future reference.
2. Record all physician visits, treatments and procedures including locations and dates.
3. Document any statement of the patient's preferences for treatments and/or funeral arrangements and include dates. It is sometimes difficult to remember verbal statements when you are under stress.
4. Where all legal documents, financial information and related materials are kept.

IV. Communication Tips

A. With Health Care Professionals

We know that at times it can be difficult to know when to call, who to call and what to ask of health care professionals. Crowded days and other responsibilities may limit the time that you have available to wait for return calls.

It may be helpful to clarify with your physicians who to call for what questions, phone hours and what constitutes an emergency call. Does the office have a voice mail, fax or an email question line? If you talk to the office secretary, be specific about what you need to know and why. Be sure to leave your phone number/beeper number/cell phone number and what times to try to reach you.

When you do reach the health care professional, be prepared:

- . • Have a written list of questions
- . • Be able to explain what you need to know and why.
- . • Be clear and specific.
- . • Concise questions will result in better answers.
- . • Avoid distractions. Turn off radio/TV, etc.
- . • Have a pen and paper handy for notes.
- . • If you do not understand the answer, ask to have it restated more clearly. You are not expected to interpret medical information.

- . • Repeat what is said to make sure you understand the information.

If you are in a face to face meeting

- . • Make room for the consultant to sit down.
- . • Turn off television.
- . • Ask how much time they have to spend with you. This will help you prioritize the time.
- . • Express how you are feeling. Be honest in your answers.

B. With The Patient

Communication can be difficult at any time but especially when dealing with the unknown. In an effort to avoid pain associated with possible loss for you and your loved one, you may say things that put off the conversation. One of the most loving things you can do is to be open to what the patient needs to say. Use the time you have to talk about what is important and to offer the support the patient needs.

Here are some alternatives you can use:

When you think you want to say:	Try this instead:
“Dad, you are going to be just fine.”	“Dad, are there some things that worry you?”
“Don’t talk like that! You can beat this!”	“It must be hard to come to terms with all of this.”
“I can’t see how anyone can help.”	“We will be there for you, always.”
“I just can’t talk about this.”	“I am feeling a little overwhelmed right now.”

	Can we talk later tonight?"
"What do doctors know? You might live forever."	"Do you think the doctors are right? How does it seem to you?"
"Please don't give up. I need you here."	"I need you here. I will miss you terribly. But we will get through somehow."
"There has to be something more to do."	"Let's be sure we get the best of medical treatments, but let's be together when we have done all we can."
"Don't be glum. You will get well."	"It must be hard. Can I just sit with you for a while?"

Adapted from: *Handbook for Mortals: Guidance for People Facing Serious Illness* by Joann Lynn, MD and Joan Harrold, MD. 1999 – Oxford University Press. Used with permission of Joanne Lynn, MD.

Social workers and other counselors are available through Inova hospitals, skilled nursing care centers, and home care to help you with communication issues.

Inova Alexandria Hospital – **703-504-3580**

Inova Fairfax Hospital – **703-698-3508**

Inova Fair Oaks Hospital – **703-391-4772**

Inova Loudon Hospital – **703-858-8017**

Inova Mt Vernon Hospital – **703-664-7238**

Inova Home Health – **703-916-2800**

V. Symptom Management

There are a great many symptoms that your loved one may experience throughout the course of illness. This section will give you some general information and guidelines about how to manage some of the most common symptoms:

- . • Pain
- . • Fatigue
- . • Dyspnea – Breathing Problems
- . • Gastrointestinal Complications
- . • Skin Problems
- . • Psychological Complications
- . • Confusion

You should always check with the doctor prior to treating the patient in order to ensure proper care of his/her problem.

Pain

Your loved one may be in pain if he/she:

- . • has decreased appetite
- . • has lost interest in regular activities
- . • is crying and upset about discomfort
- . • grimaces or winces when moving
- . • stays in bed and doesn't get dressed
- . • has difficulty sleeping
- . • is tense and tries to avoid movement

Pain can cause people to feel depressed and anxious, just as depression and anxiety can make pain worse. Because many of the signs of pain are the same as those of anxiety and depression, you need to know what is causing these symptoms and to seek treatment for them in order to stop further suffering. All types of pain can be treated safely and effectively using many types of treatments, including medication and non-drug treatments. Pain treatment needs to be tailored to the individual. What works for one person may not work for the next. Pain can be treated through the use of one or a combination of the following:

Drug therapies

Anti-inflammatory drugs – for mild pain and include aspirin, ibuprofen, acetaminophen. Some may require a prescription.

Opioids – for moderate to severe pain and require a prescription. May include morphine, methadone, and hydrocodone.

Adjuvant analgesics – used to treat conditions other than pain but can relieve some painful conditions. May include antidepressants, anticonvulsants, anesthetics, and corticosteroids.

- . • Psychological approaches (relaxation training, distraction, biofeedback)
- . • Rehabilitation therapies (physical therapy, occupational therapy)
- . • Anesthetic treatments (nerve blocks, spinal cord stimulation)

Facts About Pain Medication

Many patients do not follow their pain management regimens due to misconceptions about tolerance, physical dependence and addiction to pain medications. You, the caregiver, must know the facts about pain medicines so that you can help your loved one achieve the best possible pain relief. Here are the facts about some common myths you've probably heard.

MYTH: "If the patient takes narcotic medications, he/she will become addicted."

FACT: Addiction is characterized by the compulsive use of drugs for their psychological effects; the drugs are causing harm to the person, but are still taken. It is rare for pain patients with no history of substance abuse to become addicted to pain medication-including opioid drugs, such as morphine. Many people confuse physical dependence, which is the occurrence of withdrawal when the drug is stopped, with addiction.

MYTH: "If the patient no longer needs the medication, he/she will go through severe withdrawal when trying to stop it."

FACT: Withdrawal is a physical phenomenon that means the body has adapted to the drug in such a way that a ‘rebound’ occurs when the drug is suddenly stopped. All people who take opioids for a period of time can have this withdrawal syndrome if the drug is stopped or the dose is suddenly lowered. This can be prevented by slowly tapering the use of a drug over time. Possibly having withdrawal is not the same as being addicted and is usually no problem at all.

MYTH: “The patient will develop a tolerance to his/her medication and will have to keep taking more and more until he/she is immune to it and it doesn’t work anymore.”

FACT: Tolerance to opioid drugs occurs but is seldom a clinical problem. Tolerance means that taking the drug changes the body in such a way that the drug loses its effect over time. Most patients’ doses are gradually increased until pain relief is obtained, then they stabilize at this dose for a long period of time. If doses need to be increased because pain returns, it is more commonly due to disease factors than to tolerance.

MYTH: “Pain medication should be saved and used only when pain is severe.”

FACT: Pain medication should be given on a regular schedule so that there is a stable amount of medicine in the body to keep the pain away. By taking medication before the pain becomes unbearable, the patient can get better relief with lower doses and fewer side effects.

MYTH: “The patient will not be him/herself on the medication and will no longer be available to participate as a family member.”

FACT: Although opioids can make people sleepy and cloud their thinking, this side effect is usually temporary. Long-term therapy is generally associated with normal thinking. Most patients can take opioid drugs for a long period of time and be mentally normal. Patients who have been stabilized on opioid therapy and are clearheaded can drive, work and do whatever else their health allows.

When to call the doctor:

- if the patient is experiencing severe pain
- if there is an adverse reaction to pain medication
- if the patient continues to experience pain between scheduled doses of long-acting pain medication
- if the patient is unable to get up and walk due to pain
- if the patient is crying and upset about feeling pain
- if the patient avoids movement or tenses muscles when moving
- if there is decreased appetite due to pain
- if there is less desire to engage in normal activities due to pain

Before you call the doctor, prepare answers to the following questions:

- When did the pain start? Is it a new pain?
- How long has the patient had this pain?
- Exactly where is the pain located in the body?
- What is the quality of the pain (what does it feel like)?
- On a scale of 0 to 10 (with 10 being the worst pain imaginable), how does the patient currently rate his/her pain?

- When does the pain occur?
- Is there anything that makes the pain better?
- Is there anything that makes the pain worse?
- Is the pain interfering with other areas of the patient's life?
- What medications is the patient currently taking for the pain?

Web Sites:

<http://www.webmd.com/pain-management/default.htm>

<http://www.netofcare.org>

Fatigue.

Fatigue is not uncommon with chronic, debilitating illness. It does not improve with rest and can seriously affect a person's ability to function

Symptoms of Fatigue:

- generalized (whole body) weakness or tiredness
- diminished energy disproportionate to activity
- sleep abnormalities
- diminished motivation or interest in activities
- diminished activity associated with lower physical or intellectual performance (lack of focus, short attention span, memory problems)
- irritability, impatience, sadness, or other changes in mood

Treatment of Fatigue:

Identify and manage the underlying cause and using a variety of interventions, such as:

- medication
- education
- exercise
- sleep hygiene
- stress management
- nutrition

The Six "E"s to Manage Fatigue

Evaluation – Keep a journal to document the patterns of fatigue.

Energy Conservation – Plan activities by prioritizing importance and necessity.

Exercise – Mild to moderate exercise such as walking and stretching can increase functioning.

Energy Restoration – Decrease mental fatigue with diversion and distraction such as music.

Easing Stress – Relaxation therapy and guided imagery can help coping with stress.

Eating Well – A balance diet combines adequate calories and adequate fluid intake.

What You Can Do to Help:

- Encourage the patient to discuss his/her fatigue.
- Make sure that the health care team is aware of the patient's fatigue.
- Schedule tasks according to their importance.
- Promote resting between high-energy activities.
- Plan tasks more efficiently so they can be easily accommodated.
- Encourage the patient to get up or move slowly to avoid dizziness or falls.
- Serve small snacks as well as balanced meals high in carbohydrates (pasta, bread, fruit, and potatoes).
- Make sure the patient drinks plenty of fluids.
- Help the patient with difficult or high-energy tasks.
- Encourage the patient to do some light exercise every day.
- Keep the patient as active as possible during the day to foster easier sleep at night.
- Encourage rest when tired by going to sleep earlier, sleeping later, and taking naps.
- Assess anxiety levels and help calm the patient if anxiety is interrupting sleep.

Helpful Web Sites:

<http://www.mdanderson.org/publications/patient-power/broadcast-schedule/2008/fatigue-and-the-cancer-patient-webcast.html>

<http://www.cancerfatigue.org>

Difficulty Breathing (Dyspnea)

Dyspnea, or shortness of breath, is the unpleasant sensation of having difficulty breathing. It can occur for many reasons, such when not enough oxygen is getting to the body because of lung disease. When severe, it is a frightening experience for both the patient and the caregiver.

Difficulty breathing can be caused or worsened by:

- chronic lung disorders
- airway obstruction
- pneumonia
- pain
- stress/anxiety
- advanced, progressive illness
- tumor
- fluid in the lungs

• certain chemotherapy or radiation treatments It is important to recognize that while shortness of breath can cause anxiety, anxiety can also cause and worsen breathing difficulties. However, there are some things that you can do to help the patient avoid this cycle.

Treatments for dyspnea:

1. Medications
 - Bronchodilators – open up air passages in the lungs
 - Steroids – reduce inflammation, which opens air passages
 - Opioids – can directly lessen the sensation of breathlessness

- . • Anxiolytics – calm patients and slow their breathing
- 2. Non-Drug Treatments
- . • Relaxation exercises – helps reduce emotional and physical stress
- . • Deep breathing techniques – promote relaxation
- . • Oxygen – a machine supplies extra oxygen to the body, which helps the patient breathe easier
- . • Positioning – sitting upright allows gravity to assist the patient in breathing
- . • Increased room air ventilation – good air circulation makes it easier for patients to breathe
- . • Psychosocial support – addresses the impact of anxiety and stress on breathing problems

What You Can Do to Help:

Remain calm.

Stay with the patient and offer reassurance.

Maintain bed rest for the patient.

Raise the head of the bed or add pillows to an upright position.

Promote air circulation in the room.

Use a fan to create a light breeze in the face of the patient.

Encourage deep breathing.

Offer prescribed medication.

Maintain prescribed oxygen.

Use room humidifier or vaporizer to help loosen secretions, if necessary.

Gastrointestinal Symptoms

Gastrointestinal symptoms include problems such as: Nausea – feeling queasy, sick to one's stomach Anorexia – loss of appetite Vomiting – throwing up Constipation or Diarrhea Cachexia – severe weight loss

They may be caused by a number of illnesses, treatments, and medications: Cancer and AIDS Radiation Therapy Dehydration Chemotherapy Certain Foods Opioids, Antibiotics, and other drugs Lactose (milk) Intolerance Emotional Distress and Anxiety Surgery Taste Changes

How You Can Help Nausea and Vomiting

- Encourage the patient to take prescribed anti-nausea medication.
- Fix the patient frequent, light meals throughout the day.
- Serve foods cool or at room temperature.
- Avoid fried foods, dairy products, and acidic foods (fruit, juice, vinegar).
- Stay away from spicy foods.
- Make sure the patient's mouth is kept clean.
- Offer chewing gum or hard candy.
- Take the patient outside or open a window for fresh air.
- Encourage rest and relaxation,
- Make sure the patient drinks enough clear liquids, sipped slowly, to prevent dehydration.
- Avoid unpleasant or strong odors.
- Distract the patient with music, television, or other activities.

Constipation

- Discuss the use of laxatives and stool softeners with the doctor and follow a regular schedule as directed.
- If the doctor agrees, give the patient foods high in fiber (whole grain cereal and bread, dried fruit, nuts, beans, and raw fruits and vegetables).
- Make sure the patient drinks enough liquids (up to six to eight glasses per day).
- Offer prune juice, hot lemon water, tea, or coffee, which may stimulate the bowels.
- Encourage daily exercise, such as walking (in keeping with the doctor's advice).

Diarrhea

- Give medicine for diarrhea as directed by the doctor.
- Replace lost fluids and nutrients by offering clear liquids (clear juices, water, broth), often and in-between meals (two to three quarts per day).
- Serve foods low in fiber and high in potassium and protein (eggs, bananas, applesauce, mashed potatoes, rice, and dry toast).
- Serve many small meals throughout the day rather than three big meals.
- Avoid serving foods that may increase bloating (vegetables, beans, fruits).
- Avoid serving fatty or acidic foods (fatty meat, fried food, spicy food).
- Limit caffeine intake (coffee, tea, soda with caffeine, and chocolate).
- Avoid serving dairy or milk products.

Loss of Appetite/Weight Loss

- Do not force feed the patient.
- Do not get angry if the patient does not want to eat.
- Prepare familiar favorite foods.
- Try light exercise or walking before meals.
- Encourage eating meals at the table with others.
- Serve meals over a prolonged period of time in a relaxed environment.
- Place meals on smaller plates with smaller servings more frequently.
- Cover up unpleasant odors.
- Serve a glass of wine before meals to stimulate appetite.
- Offer frequent, high protein, high calorie snacks (pudding, ice cream, milk shakes).
- Try new spices or flavorings for foods.
- Prevent early feelings of fullness by serving beverages between meals, not with meals, eating slowly, and avoiding too many vegetables and carbonated drinks.

Skin Problems

Skin problems such as dryness, rash, itching, sores, ulcers, and swelling can be recognized and treated quickly in order to reduce discomfort and the risk of infection.

Common Skin Problems

Pressure Sores – Blisters or breaks in the skin caused when the body's weight stops the flow of blood to a certain area, causing a breakdown in the skin.

- Most likely to affect patients who are bedridden, low weight, malnourished, or dehydrated
- Usually occur in bony areas, such as the head, elbows, heels, hips, shoulders, and tailbone
- Sores are made worse when the patient rubs against his/her sheets
- Look for red areas, cracked/broken skin, an open sore, yellow colored stains on

sheets, and pain at pressure points and report to the patient's doctor

How to Help

- Keep skin dry and clean.
- Check skin daily.
- Try to turn a bedridden person every few hours.
- Encourage the patient to get out of bed as much as possible.
- Never leave the patient lying or sitting in wet clothes or bedding.
- Make sure the bedding is not wrinkled or irritating the patient's skin.
- Promote a balanced nutritious diet, high in protein (chicken, tuna, cheese).
- Do not open or pop blisters.
- Put dry clean gauze on any open areas.

Ulcers – A crater-like lesion on the skin.

- Usually caused by inflammation or infection of the area, or an underlying condition that may affect the skin's ability to heal

How to Help

- The skin area should be kept clean and observed for signs of infection (pain, redness, drainage that looks like pus).
- Follow treatment instructions from the doctor, which may include wet dressings and topical antibiotics to control infection in open ulcers.

Edema – Swelling of the skin that is caused by water and salt retention

- Can occur from certain medications; heart, liver, or kidney failure; malnutrition; and obstruction of veins or lymph nodes
- Look for swelling of feet and lower legs, feeling of tightness in hands, swollen or distended abdomen and report to the patient's doctor.

How to Help

- Keep feet elevated when lying in bed or sitting.
- Take medication, and restrict fluids or salt intake, as prescribed by the doctor.

Itching – The desire to rub or scratch the skin

- Can be the result of dryness, allergies, and side effects of medications or treatments

Rash – Bumpy, red, itchy skin

Commonly caused by an allergy, irritation, radiation therapy, or certain infections.

How to Help

- Suggest bathing with cool water.
- Add baking soda to bath water.
- Apply a cool moist cloth to itchy areas.
- Wash sheets and towels in mild laundry soap and change daily.
- Avoid harsh laundry detergents.
- Apply medications prescribed by the doctor for skin irritations.

Dryness – Rough, flaky, red, sometimes painful skin due to a lack of water or oil in the layers of the skin

- Can be caused by dehydration, cold weather, heat, and side effects of treatments (such as chemotherapy and radiation)

How to Help

- Add mineral or baby oil to a warm bath.
- Apply moisturizers.

- Make sure the patient drinks enough (eight to ten glasses per day).
- Prevent dryness by not scrubbing skin while bathing and gently patting skin dry.

Psychological Complications

Living with a chronic illness may be associated with intense feeling of fear, worry, sadness and grief. It is normal for you and the patient to experience such emotions. Overwhelming anxiety and depression that does not go away is a psychological problem and may require treatment. Both conditions are highly treatable but you need to bring your concerns to your doctor's attention.

Depression

- persistent sadness or feelings of guilt, worthlessness, hopelessness, and helplessness
- tiredness or decrease in energy
- loss of interest or pleasure in ordinary activities
- sleep problems
- loss of appetite or overeating
- tearfulness or excessive crying
- problems concentrating, paying attention, remembering, or making decisions
- irritability
- thoughts of suicide or suicide attempts Call the doctor if these symptoms last for two weeks or more, or if they are severe enough to interfere with normal functioning.

Anxiety

- verbal expressions of anxiety, nervousness, panic or feeling like something is going to happen
- verbal denial of obvious tension or anxiety
- difficulty solving problems
- muscle tension
- trembling and shaking
- difficulty breathing
- upset stomach
- sweaty palms
- racing heart
- headaches
- gets angry easily

How You Can Help –

Let your loved one express his/her feelings

Encourage the patient to identify any concrete causes for the feelings

Actively listen and try to understand what the patient is feeling

Provide support and encouragement

Make sure the patient knows that it is normal for him/her to experience these feelings

Encourage the patient to participate in an exercise program

Encourage the patient to speak to a professional counselor or therapist who has experience with chronic illness

Promote the use of relaxation techniques

Recognize the signs of psychological symptoms so that you know when it is necessary

to call the doctor

Encourage the patient to take antianxiety or antidepressant medications as prescribed by the doctor

Try To Avoid

Forcing the patient to talk if he/she is not ready.

Telling the patient how he/she “should” feel

Assuming that it is your fault if the patient is feeling depressed

Feeling that you must cheer the person up in order to be helpful

Trying to reason with the patient

Trying to talk the patient out of how he/she is feeling

Confusion

When your loved one appears confused, you can feel helpless and frustrated. Confusion may be temporary or progressive and irreversible. Dementia and delirium are two common causes of confusion. It is important to understand the source of the confusion in order to manage it.

We lack data about the caregivers's perspective on the end-of-life (EOL) phase of GBM patients to improve counseling and support. In this study we investigated the experiences of 52 caregivers of deceased GBM patients treated in Austria. We used a questionnaire developed by the University Medical Centre of Amsterdam for exploration of the EOL-phase in glioma patients. The caregivers (17 men, 34 women) completed the questionnaire in median three years after the patients's death. 29 % of caregivers reported that they felt incompletely prepared for their tasks, however, those with higher education comprehensive, objective reports based on data, facts and the voices of patients, caregivers and those who work each day in the health system. As well, we make recommendations on how to improve care using the best evidence. Finally, we support large scale quality improvements by working with our partners to facilitate ways for health care providers to learn from each other and share innovative approaches. Suggested citation: Health Quality Ontario. Palliative Care at the End of Life. Toronto: Queen's Printer for Ontario; 2016. On the cover: Karen Nicole, courtesy of Healthy Debate: Faces of Health Care (<http://healthydebate.ca/faces-health-care>).