



Suggestions from a Caregiver

Support Part 9 - Selecting a Specific Service Hospice Step Three

by Elizabeth Howe, M.B.A.

Last time we provided some information to help you and your loved one select a primary care physician who would honor your loved one's end-of-life wishes, medically and comfort-wise. This time we will investigate the third step of the three-part process, selecting a hospice service that will, working with our primary care physician, honor the wishes our loved one has so carefully thought out.

Hospice emphasizes palliative rather than curative treatment; quality rather than quantity of life. Palliative care is specialized care that focuses on pain, symptoms and stress of serious illness/conditions. Hospice helps both the loved one and their family deal with the mental and emotional aspects of the final journey. Professional medical care along with sophisticated symptom relief is provided. Support is based on our loved one's wishes and condition and the family's needs.

The patient and family, as well as primary caregiver (if not a family member), should be included in our loved one's care plan. The primary caregiver plays a key role. That person is the one likely to be most in tune with the ever-changing, sometimes subtle, nuances of our loved one's progression as they walk the final months of life's journey.

Selecting a hospice service should be done now. The selection, however, is one that you would want to reaffirm as the time to actually engage the service approaches. Changes in management and licensure status can dramatically affect the day-to-day running of the hospice.

First determine whether the service is accredited by a national agency such as the Community Health Accreditation Program (CHAP) and/or TJC (The Joint Commission), formerly Joint Commission on Accreditation of Health Care Organizations (JCAHO). These organizations address an organization's performance in key functional areas. Accreditation is highly desirable. You and your loved one must decide if accreditation is essential.

Second, does the organization have a full time Medical Director, not an interim, who is a physician? The Medical Director has an obligation to make sure that each hospice patient receives all the medically indicated services needed to control the symptoms of the patient's terminal illness. According to the Federal regulations (42 CFR 418.54), the Medical Director "assumes overall responsibility for the medical component of the hospice's patient care program."

The Medical Director serves as a secondary check on the Attending Physician (Primary Care Provider you selected) to make sure that the patient receives the very best of care. In some instances, an Attending Physician may not order the medications needed for the patient's comfort or to control the symptoms adequately. The nurse case manager will communicate the patient's needs to the Attending Physician. If the Attending Physician refuses to provide for the patient's needs, the Medical Director should be consulted to intervene on the patient's behalf.

Next, personally interview the hospice services. It should be easy to get an appointment to speak with someone about their hospice's services. If you have someone to take with you, either the loved one if they are still able or a trusted friend or family member that is beneficial. Don't forget to take paper and something to write notes, as there are a lot of questions. If you need an answer repeated, don't hesitate to ask. If the

interviewer is nervous with your note-taking, let them know you would be happy to speak with someone else if they prefer.

Here are questions to ask and answers you should get:

1. **What is the title of the person you are interviewing? What is their experience with providing hospice service?** Ideally the person who is answering your questions is able to answer the interview questions from experience, not from a script. If they do not have hands-on experience, assure them that if they need to have you speak with someone else as the interview progresses, you would be happy to do so.
2. **What is the mission statement of your organization? How does this statement translate into day-to-day hospice services/support for my loved one and myself, the primary caregiver?** This answer you will need to judge for yourself, but be sure the answer SAYS something specific and does not just 'sound good.'
3. **What initial and ongoing training is provided for/expected of each separate area of the hospice team?** The answer should be specific for each role in your loved one's care, e.g. nurses, case managers, social workers, volunteers.
4. **What experience does your hospice service & staff have with:**
 - a. **Your loved one's disease/condition?** The answer should be very specific. If your loved one has a rare condition most likely any hospice will have little experience. They should say so and explain how they would address that.
 - b. **With those who no longer may speak but are aware (aphasia)?** Again, specifics, but certainly they must mention use of the 'smiley face' pain scale which is a common tool to assess level of pain in those who cannot speak.
 - c. **With those who are sometimes/often, but not always confused?** The answer should be specific and include relying on the primary caregiver who is on-site and monitoring our loved one.
5. **Does your hospice service work routinely with (fill in Primary Care Provider's name)?** This is for information only.
6. **Who is involved in the loved one's care plan?** This should include the standard participants such as nurse case manager, primary care provider and social worker. But what you are listening for in particular is the inclusion of the primary caregiver in particular. If they do not include the primary caregiver, this is not the service for your loved one.
7. **How are initial assessments of the loved one conducted by the nurse and who is present?** This should be specific. The primary caregiver should be allowed to be present, in particular if your loved one has aphasia and cannot speak or they speak by repeating the last thing said. The nurse evaluator must be open to tapping into the primary caregiver's in-depth knowledge acquired through experience with our loved one.
8. **What is the role of the primary caregiver in the ongoing condition assessment of the loved one?** The answer should specifically acknowledge the important role of the primary caregiver as the member of the case management team who is always assessing our loved one's condition, doesn't just come periodically.
9. **How is the pain level of the loved one determined?** They should be specific and should be aware that in the case of long-standing pain and/or neurological conditions our loved one may not exhibit a 'scrunched face' or similar outward signs as a person would when they suffer a traumatic injury. Again they should specifically mention the role of the primary caregiver in this determination.
10. **Is there education for the family/primary caregiver on what to expect and tools to use as your loved one's condition deteriorates?** This should be specific, e.g. what the normal progression is for someone who deteriorates/is dying to best provide comfort measures for your loved one and reassure family, what to do when medication can no longer be given by mouth and so on. They should mention who provides this information to assist the caregiver as they assist the loved one. They should indicate they are proactive, that is, provide information in general and in particular as your loved one's condition deteriorates. The primary caregiver may will not know what to ask/when.

11. **How is communication handled routinely, as well as when the loved one's condition suddenly changes?** The primary caregiver should be part of the regular care plan evaluation and be able to summon advice or emergency on-site assistance 24/7.
12. **What is the typical turnaround time when the caregiver calls in with a question?** The answer should be reasonable. For example, there may not be someone immediately available as they are with another client. The answer should include some information on triage, that is, a determination of whether the caregiver's question/concern is something that should be immediately addressed either by phone or an on-site visit.
13. **Is physical care such as bathing provided by those in your employ or do you have another service you bring in?** The answer may not matter, depending on the answer to the next question.
14. **What is our recourse if we have concerns about any of the services? How and to whom do we convey our concerns?** The answer should be specific, but may depend on which team member/specific service the concern is with. Ultimately the primary caregiver should be able to go to the Medical Director for resolution of concerns.
15. **Ask again for each of team member positions, including social workers and volunteers. Write these down. Ask: What support may we expect from (ask one-by-one, e.g. the social worker, etc.?)** The answers should be specific.

If you do not get ALL the answers as noted above, you may need to:

- a. Ask to speak with the Medical Director or someone else and ask them the questions. The person initially designated to speak with you may not be adequately representing their hospice service.
- b. Ask to speak with one of the nurses and ask them the questions. You should get the same answers from the nurse as you got from your first contact person and the Medical Director.
- c. Find another hospice service.

NOW you and your loved one have the information you need to select the hospice service to eventually use.

While so much of life we cannot control, the steps to selecting a hospice ARE something you can do to ensure the final steps of the journey are as pleasant and positive as they can be. Further change or more tasks to take on are hard anytime, and in particular as you and your loved one face the loss of each other and of your plans and dreams. Preparing NOW will ensure that you have taken the steps necessary for end end-of-life experience you deserve. Next time we will look at when to actually begin using the hospice service we have selected.

NOTE: At this time, this series will not include or factor in selecting a hospice facility. Some communities offer a hospice service and a separate facility where the loved one may hospice in an atmosphere of total care—mental, physical, emotional, spiritual—as they prepare for their final journey.

In Lincoln Nebraska this choice is basically non-existent. There is only one dedicated hospice facility with five beds for a population of 250,000 not including the surrounding geographic area! Hospices in this area provide service in-place at home or at whatever care facility our loved one may reside in at the time hospice become appropriate.

Suggestions from a Caregiver

Support - Part 8

The Primary Caregiver – Hospice Step Two

Last time we provided some resources to help determine your loved ones with end-of-life wishes, medically and comfort-wise. This time we will investigate the second component of the three-part process of selecting a hospice service that will honor the wishes our loved one has so carefully thought out.

The second step, once you know end-of-life wishes, is selecting a primary care doctor whose idea of hospice is the same as yours and who will let the hospice professionals who see and work daily with those who are terminally ill DO their jobs. Dave and I did not understand the role of the primary care doctor. Despite extensive research, albeit too late to help Dave, we did not find ANYTHING on the important role of the primary care doctor! Dave's primary care doctor did well with establishing a diagnosis, respecting his dementia, working with the aphasia (difficulty verbally communicating) and through me as his 'voice' when other medical conditions arose over the time of our journey. We thought we were set AND did not even know there were other questions to ask.

Hospice emphasizes palliative rather than curative treatment; quality rather than quantity of life. The dying are comforted. Professional medical care is given, and sophisticated symptom relief provided. The patient and family are both included in the care plan and emotional, spiritual and practical support is given based on the patient's wishes and family's needs.

When in hospice, you must have a 'local' doctor, a role generally fulfilled by your primary care doctor. Even if you consider your main doctor an out-of-town specialist, you will need a local doctor to fulfill the 'doctor' role once you are working with hospice. What if your primary care doctor does not agree with or understand the goal of hospice to provide care when there is no hope of recovery, perhaps months not just days? What if your primary care doctor does not believe in symptom (including pain) relief at levels recommended by the hospice professionals? Then you will not have a positive hospice experience—either our loved one or the family, who must hopelessly watch our loved one suffer.

Changing primary care doctors is difficult. But once in hospice and you find out your primary care does not ascribe to the 'comfort' and 'palliative' components of hospice care, changing physicians is basically impossible. How do you find out if your primary care is the 'right' one now your life circumstances have changed? Ask questions. BUT be sure you ask questions in such a way that you don't lead your primary care into the answer you are looking for. To make the 'interview' seem more like a discussion, I suggest you have the interview coincide with a regular visit for something—physicals, cold/sore throat, medication evaluation, whatever you normally visit for. Then you can mention that since, your loved one has a terminal illness you have been wondering about a few end-of-life things. That will make it sound like you are just asking their opinion...which you really are. Following are some interview question suggestions:

- What is hospice? (The definition should be close to the above, or similar that you can find on the internet.)
- When do you consider entering a hospice program appropriate? (The answer should be: Once the loved one has no more treatment options to pursue. Hospice is appropriate any time thereafter, but certainly as pain increases and/or physical functionality decreases. Generally the statement is 'when the patient has 6 months left to live.' However, for someone with Alzheimer's or the other dementia diseases, there is no clear documentation on when that might be. For your loved one, '6 months to live' is NOT a good answer.)
- IF you get the '6 months to live' answer, ask: How would you determine '6 months' with this particular disease for which end-of-life is not well documented? (The answer should refer to not more treatment

options, pain increasing and/or physical functionality is decreasing to a point where hospice services would be beneficial to the family as well as to the loved one. There is no reason to and know way to really know what is '6 months.')

- Do you work with a particular hospice? (The answer should be 'no' and the primary care of their staff should not try to steer you toward a particular hospice service.)
- What is your philosophy on pain control? (The answer should be to keep the loved one comfortable and pain-free. If the answer does not include trusting the advice and experience of the hospice professionals, then move on to the next question.)
- What is your role when working with the hospice nurses? (If the answer does not include trusting the advice and experience of the hospice professionals, and consulting with the family who is the primary caregiver, then move on to the next question.)
- What is your response generally to the recommendations of the hospice nurses? (The answer should be to trust their advice and follow their recommendations. The hospice personnel are the medical professionals actually seeing your loved one. The situation can change rapidly. The hospice professionals deal with end-of-life daily and they have the experience and expertise to make appropriate recommendations.)

If you do not get ALL the answers as noted above, you need to find another primary care doctor. Once you've established a primary care doctor whose philosophy of hospice and medication use is in sync with your views, you need to select a local hospice service. Not all hospice organizations are created equal. This topic will be covered in the next newsletter.

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Suggestions from a Caregiver

Part 7 - End of Life Decisions

Hospice - Step One

When is the right time to pick a hospice? As Dave and I found out, belatedly, the right time to start picking a hospice is right away. Start the three-part process when you complete/review your legal documents, perhaps even before you interview possible care facilities. Why? It is important that the care-receiver has their wishes honored.

Many things in life are out of our control. But we can have a say in how we are treated when seriously ill at the end of life if we take the right steps. In order to pick a service which will honor our wishes for end-of-life care and comfort, we need to determine what those wishes ARE.

There is an excellent resource called *Five Wishes* living will which is available through <http://www.agingwithdignity.org/>. Our attorney recommended that we first complete a will, with extra witnessed questions to assure there would not be a question of competence, get a durable POA (power of attorney - financial and medical). After those steps is the time to complete the *Five Wishes*. *Five Wishes* is considered a legal document in Nebraska. We wrote on the front of our document that the instructions inside did not supercede, but rather added to our POA. Once completed, we both provided our *Five Wishes*, along with our POA to all hospitals and doctors we saw during our journey - Dave's to his and I to mine.

The Alzheimer's Association-Great Plains Chapter has a number of useful pamphlets on a variety of topics. One pamphlet in particular, *End-of Life Decisions, Honoring the Wishes of the Person with Alzheimer's Disease*, was a great help to Dave in understanding what Alzheimer's patients die of and the death process. This pamphlet helped him make decisions while he could. He decided on what he did NOT want, treatments that would not change the outcome and merely prolong the inevitable or add to his discomfort rather than comfort at end-of-life. This Alzheimer's Association pamphlet and Dave's *Five Wishes* helped me come to terms early with Dave's end-of-life wishes, making them easier for me to carry out when the time came.

The *Five Wishes* document from the Aging With Dignity organization has five sections, hence 'five' wishes. The sections are entitled: *The Person I Want to Make Care Decisions for Me When I Can't*; *The Kind of Medical Treatment I Want or Don't Want*; *How Comfortable I Want to Be*; *How I Want People to Treat Me*; and *What I Want My Loved Ones to Know*. The questions in this document helped Dave and I even KNOW what some things to think about might be.

After completion, we each shared our individual wishes with our families as well as our POA designee. I think it helped our family to know ahead of time what Dave's wishes were, so they could accept his decisions well ahead of time. Of interest: While Dave decided originally that he did not want special music while dying, as he lay at home on his deathbed he asked our son to play the piano for him. That was the only thing that changed from his carefully thought out *Five Wishes*.

Suggestions from a Caregiver

Support, Part 6 - Grief

This article is in memory of my beloved husband, Dave, who ended his journey on this earth recently. It is also dedicated to all our friends at the Great Plains Chapter of the Alzheimer's Association who helped us on this journey and our friends who made every day a little brighter because they were there walking the path too.

What is grief? Grief is the response to loss, any loss, but in this context we are talking about someone to whom a bond was formed—spouse, parent, sibling, good friend, and other relative. We begin our journey, as do most reading this, when we know 'something' is not 'right'. We walk a path of alternating doubt and hope, reaching out for understanding of what is occurring and acceptance of our 'difference' by others as well as ourselves.

Along the path we found the Great Plains chapter of the Alzheimer's Association. The association and all officially associated with the chapter help us learn, accept, and even grow as they help us find new resources locally and nationally through the Alzheimer's Association web site. The local chapter sponsors support groups. At first we think the support group is for us—to support us, guide us, provide resources. And then we come to realize that the support group IS for us, but not just to *receive* support but to *give* support to others as we all grow new friendships and share our experiences, triumphs and losses with each other. The association and the support groups help us deal with our very real daily grief.

People think of grief at death as occurring when someone's body leaves this earth. While there is a 'grief' that occurs with that finality, those with a terminal illness begin the grief process at once, often before diagnosis, as little and sometimes bigger things just leave. One day an ability is here and the next it is gone. Then we experience what is called 'anticipatory grief.' We know other things will be leaving as well and need to plan for handling 'the next step' while dealing with the intricacies of today's journey.

Grief is very complex. While there certainly is an emotional component, there are other components we must deal with. If we do not consider and address the physical ramifications, we can and caregivers often do, become physically ill ourselves. This negatively impacts our own lives, but also limits our ability to help our loved ones as we move along our journey's path.

There are cognitive components too. Sometimes if we have not taken good enough care of our own mental health we experience symptoms of mental loss. When we notice those abilities and focus are becoming more difficult to maintain, we need to focus on finding the support for ourselves our loved one can no longer provide. Often by talking with others in the Alzheimer's Association or other support groups for caregivers we can get hints of what we can fit into our own lives to help smooth the path. And sometimes just hearing about the path of others makes our own path seem less onerous!

What to do? **Realize** you are grieving. **Allow** yourself to grieve. **Go** to a support group. **Seek and accept** help—emotional (someone to call) and physical (help with tasks, respite, advice on 'how to do' this or that task you must now take on). **Simplify tasks** in our lives. If a task does not need doing, don't do it at all, or at least do it only half as often. It gets easier to let things go with practice. Do the windows REALLY need cleaning twice a year? My windows all said 'no.' **Simplify relationships** in your lives. If it becomes apparent that certain people, even family, are not being supportive and/or are negatively impacting your journey, then decrease or discontinue your contact with them.

Remember what is most important in life...your loved one and yourself and the time you have left on your journey. Cherish every day you have together. Celebrate the triumphs, even the 'small' things we used to take for granted like self-care. Celebrate friends and family who appreciate you for who you are, not who you used to be or who they want you to

be. Celebrate or develop spirituality, a sense that there is something 'bigger' that is good and all-caring. Celebrate every second with your loved one.

Excellent resources, easy to read in small snatches:

James, John W. and Russell Friedman. *The Grief Recovery Handbook*. New York, New York: Harper Collins Publisher. 2009.

Rando, Therese A. Ph.D. *Grieving: How to Go on Living When Someone You Love Dies*. Lexington, Massachusetts: Lexington Books. 1988.

Suggestions from a Caregiver

Support, Part 5 - The Elephant in the Room

The Alzheimer's Association, in addition to others working with dementia, stresses the importance of keeping up an active social life. These same sources also caution that the individual with dementia and their caregiver must be prepared to be 'dumped' by some or all of their current friends. We have come to the realization that perhaps being 'dumped' by friends is something we can control!

Over the past couple years of Dave's and my journey, we have kept all our friends, and we've given a great deal of thought as to why that may be. Certainly we want to credit our friends with being loving, caring people. And our psychologist says that Dave and I are to give ourselves credit for maintaining an optimistic, positive attitude that others find appealing. Humans are inherently drawn to comfort sad people, but can seldom tolerate more than a few minutes in the presence of the seriously depressed...and a bit longer in the presence of those who are continually sad most of the time, although perhaps not depressed. Talking about the trials of your condition or that of your loved one, to the exclusion of other topics has to be mentally and emotionally draining for friends, as it is for the caregiver and care-receiver.

We've come to believe that perhaps one of the biggest reasons friends 'dump' those with cancer, dementia and other life-altering conditions is the 'elephant in the room.' Too often those of us with such a condition in our family get so stuck in the denial and desire to be 'normal' that we leave the elephant squarely in the middle of the room. We do not acknowledge our condition in a matter-of-fact way, as we would say, the number of children or grandchildren we have, or what we had for lunch.

That leaves the friends with little recourse to relieve THEIR anxiety over a situation that they can clearly recognize is NOT 'normal', especially as the condition progresses. While human beings generally care about other people, the tendency is to NOT hang around with those who make us feel uncomfortable, whether we know why we feel uncomfortable or not. When faced with continual discomfort we tend to come up with excuses to have less and less contact with those people or that situation.

We all strive for control in our lives. Working to focus on the positive, no matter how 'small' that positive might seem to others, is something we CAN control. Helping our friends feel comfortable with the 'new' us by acknowledging our condition matter-of-factly is something we CAN control.

We all need support as we journey life's path. Maintaining previous friendships is one way we can achieve support. That support may just be a break from dealing with the challenges we now face by talking about ordinary things as we used to, hearing about our friends lives and concerns, discussing the Huskers or the weather. For more condition-specific support there are other resources.

We have talked before about the benefits of attending the Great Plains Chapter twice-a-month support group for individuals with dementia and their caregivers. The social aspects of this twice-monthly group are perhaps the biggest advantage to the individual with dementia and their caregiver. In this group, everyone has an 'elephant' sitting on their shoulder so it might be a good place to start becoming comfortable acknowledging the condition (elephant) that is taking us down a different path from most of our friends.

Dave and I have made several personal friends from among those we have met over time at these twice-monthly Great Plains Chapter support group sessions. We get together regularly outside of the group setting with these new friends. So we have actually added to our social network!

Now you might be wondering, "Where do I start dealing with the elephant?" You handle this situation the same way you EAT an elephant. Just begin somewhere/somehow and take one 'bite' at a time!

Suggestions from a Caregiver

Support, Part 4

We've touched a bit in previous articles about emotional support, important for the mental and physical health of caregivers. The local and national Alzheimer's Association play a vital role in the emotional support that helps us better cope with the situations we find ourselves in. Ideally each of us also has a counselor, part of the mental health community or a spiritual community we can speak with one-on-one for assistance moving along the new paths our lives have taken. The care-receiver, as long as able, ideally would have a counselor or spiritual advisor, they could speak with.

But human beings are by nature sociable creatures and we often find it helpful to talk with others in groups. How are *they* feeling about their journey? How do *they* handle this or that task or situation that arises? And sometime, just a chat about something besides the journey we find ourselves on is the most helpful and refreshing.

The Great Plains Chapter of the Alzheimer's Association sponsors a large number of Support Groups for caregivers at various locations, days, and times, to best meet the need of those of us who find ourselves a caregiver for a loved one - parent, child, spouse, sibling. Yes, in Lincoln there are parents who are caregivers for an adult 'child' with Young Onset Alzheimer's Disease.

A recent addition to the offerings is the Lincoln Support Group of care-receivers and their caregiver that meets the second and fourth Wednesday of every month, 10:30 a.m. – noon. While the group originally began as part of a grant to reach out to those with Younger Onset (age 65 and earlier), anyone that has been diagnosed with Alzheimer's or other related dementias is encouraged to attend with their caregiver. The group not only shares information on their personal journey with Alzheimer's as they are able and comfortable, but also highlights and interesting components of their daily lives that have nothing to do with the disease. Periodic special events in the early evening are also designed to reach a different segment of the Younger Onset population and their caregivers.

Attending this Support Group as work/life demands permit is a great way to learn about 'the latest', in particular as it relates to Younger Onset Alzheimer's Disease, diagnosis, genetics, and more. These meetings provide an opportunity to meet and bond with other caregivers dealing with similar concerns - children at home, juggling job and caregiving, etc. Dave and I have personally become friends with two different couples we met through this group and socialize with each of them regularly. As a caregiver, I find it helpful to my emotional health to be friends with someone I can speak frankly with, who is going through many of the same things and who understands, often without words.

One fantastic resource, available 24/7 at 1-800-272-3900, is the Alzheimer's Association 'hotline.' I've called this number late at night when none of my personal support people were up, and no counselor or clergy were available. I was put through to a very knowledgeable person who counseled me and quelled my panic so I could handle things optimally for my loved one and with the least mental and emotional stress for me.

On a final note, we caregivers need to work hard to maintain interests and some 'life' that is *NOT* about caregiving, our loved one, and their disease. Stress *IS* a killer. Those of us who have chosen to be a caregiver certainly would not want to pre-decease our loved one because we did not take care of our own emotional and physical health! Where would that leave the care-receiver? So if you can't muster the will to do things for yourself 'just because', do it for your loved one so you can stay healthy and happy for their sake. And someday there will be an 'afterward.' To continue 'afterward' for ourselves, for our families, for our friends who hold us dear, and to share the memory of our loved one who had this disease, we must have some 'life' of our own left to build on and expand.

Suggestions from a Caregiver

Support, Part 3: For the Care-Receiver

So far we have focused on support the caregiver can tap into for themselves, which ultimately helps their loved one. The focus of this article is to provide resources useful to our Loved One, in particular in the early stages of Alzheimer's or other dementias. Since the onset symptoms and progression are so different for each person, some of these tips might be useful for some time into the disease.

The national Alzheimer's Association web site is a great source of a variety of information. Go to: www.alz.org. Hover your mouse over the categories listed left to right under the Alzheimer's banner at the top of the page. Of particular note are the categories under '*Alzheimer's Disease*' and '*Living With Alzheimer's*.' The last menu item under '*Living With Alzheimer's*' is '*Message Boards*'. Click those words, register, and then visit with others through the online message boards. There is a section specifically for Earlier Onset. You can review the forum topics and add your own thoughts and comments. Or you can even chat online in a virtual 'room' so those with dementia can communicate directly with each other.

Most people are familiar with using computers for email. If you email, continue with that as long as possible. The social interaction is fun as well as beneficial. The process of composing and typing emails uses many parts of your brain. If you haven't ever done email, start. One of the best is available through Google and is called 'Gmail.' Go to: <http://gmail.google.com>, create an account and get started right away. It is very user-friendly and this service gives you lots of space so if your friends send you things like pictures, video clips, etc. you don't have to worry you will fill up your email Inbox.

If you are having trouble typing, but can use a mouse to point-and-click, a free on-screen keyboard is available FREE. Go to: <http://www.lakefolks.org/cnt/> to download the Click-N-Type virtual keyboard. It can be set up so it looks like a normal keyboard, or set up so in the upper left is the letter 'A', followed by 'B', followed by 'C' and so on. If you can't click but can 'hover', that is move the mouse so the arrow is over a letter, the keyboard can be set up to 'type' when you hover a set number of seconds.

You might think Facebook is just for the kids, but it can be a valuable social too for you as well. Go to: www.facebook.com and sign up. There are different levels of privacy that you can specify if you are not totally comfortable with any and everyone able to see your profile.

To make Facebook easy to use for anyone and make it more 'social', download a free social web browser called 'Flock.' Go to: www.flock.com for a free download. With this browser, you have the tabs just like with Internet Explorer, Firefox or whatever browser you normally use with one big difference. On the left side, there is a person's head. If you click on that, the whole left side opens a window that keeps your Facebook friends constantly in view. It's kind of like sitting in an office, but only with your friends. Throughout the day, as they update their status, their profile jumps to the top, so you can easily see who is adding something to Facebook about what they are doing that day.

Keeping a positive attitude is a good idea for everyone. One key concept to remember is EMPOWER yourself, that is, control what you can. As the condition progresses, what you can control will change. If you are having trouble, perhaps your caregiver or a counselor can help you figure out what you can control. The Alzheimer's Association provides a toll-free number so you can talk to someone there about any aspect of your condition. Call 1-800-272-3900 to access the 24/7 Helpline.

In the earlier stages, get into the habit of living one day at a time. Since progression is so different from person to person, there's really no point in spending lots of time worrying about what your life will be like over time. Enjoy what you can each and every day. Focus on what you are doing daily that is productive and you enjoy, even if it's very different from the activities you did before Alzheimer's or other dementia 'grabbed hold' of you.

Suggestions from a Caregiver

Support, Part 2

I don't know about you, but I feel more empowered gathering all the information I can, not only on Alzheimer's and other dementias, but on caregiving.

Here are a few GREAT avenues for support. I will start with some online and then let you know about local resources.

- **Alzheimer's Association (www.alz.org)**

I mentioned using the Alzheimer's Association Library and 24/7 phone in the last newsletter. The Association provides information on Care Providers from basic types to finding a care provider in your area, with a multitude of useful links. We sometimes forget we are not superheroes and cannot forge on forever alone conquering the 'beast' living inside our loved one. There will come a time when that is the best option for you as well as for the safety and comfort of your loved one. Start early on to remind yourself that someday you will need to make this decision.

The national association has a message board. It has been my experience that the focus is more on 'parents' than 'spouses', perfect for those who are caregivers for a parent or parents.

- **National Family Caregiver's Association (www.thefamilycaregiver.org)**

This site has a teleconference you can participate in for free! The teleconference focuses on dealing with healthcare and provides extremely useful information on interacting with providers in a way to optimize the diagnosis, testing and care of your loved one.

- **CAREGIVING 4 ALZ (http://geocities.com/caregiving4alz/save_the_caregiver.htm)**

The link provided is for the page "Save the Caregiver," a good place to start to help 'drive home' that statistics show we are not superheroes and cannot continue forever on our own. At the bottom of the page there are links to external resources and other topics addressed within the web site. Betty Weiss, whose site this is, has become a friend. Her loved one has passed on, but the condition never leaves us once we are touched by it.

These online resources are all well and good, but what about local resources for those times you just need to speak with someone in person?

- **Alzheimer's Association-Great Plains Chapter (<http://alz.org/greatplains/>)**

The local chapter website provides information on support groups within the extensive area covered by the chapter. There is a Young Onset Support Group in Lincoln that meets twice a month where those with dementia and their caregivers can all get together and interact at whatever level they are comfortable and capable. There are quite a number of support groups for caregivers to attend, for those whose loved one has progressed to a certain point. You can find one that fits into your schedule and in a location that is convenient. The toll free Alzheimer's Association phone number, 1-800-272-3900, reaches the local chapter during weekday business hours and the national hotline after normal business hours.

Suggestions from a Caregiver

Support, Part 1

Dealing with dementia in a loved one can be overwhelming at times, or most of the time. Not only do we have our own lives to conduct, we are trying to do the best we can for our loved one. All the time we are also grieving the loss we both are undergoing. You about get used to one level of effort and things change and get harder.

As caregivers we are advised to reduce stress, keep a life of our own not involved with caregiving, exercise, and eat properly. The focus of this article is reducing stress.

The caregiver's key to reducing stress and keeping THEIR sanity is support support support ...and the most important...SUPPORT. Many articles tell us that if we don't take care of ourselves we can, and do, become statistics ourselves. We die earlier than our non-caregiving peers, or worse yet before the loved one we are caring for.

One of the useful things I've been advised to do is make a list of all my friends, family and acquaintances. Next to each name I indicate what role they can play in reducing my stress level through support in three categories:

1. 'D' goes next to the names of those who can be counted on to 'Do'. There are and will be things we inevitably will need done or need help doing or leaning to do ourselves.
2. 'L' goes next to the names of those who can be counted on to 'Listen.' We need people we can talk to, even if we end up saying the same things over and over. I suggest, if possible, you find one or two you can literally call 24/7.
3. 'C' goes next to the names of those who prefer to 'Continue on' as if nothing has happened. They prefer not to talk or hear about the nasty things going on in our lives and the life of our loved one. BUT they are willing to continue to be our friend. These people are essential for those times when we just want to 'get away' and pretend to be like everyone else (non-caregivers).

Think about those you know in all avenues of your life - work, professional associations, family, friends, church. Be sure to include all people you know. You might be surprised at the number of potential support people you have. Don't forget to think about those who know/knew your loved one. Often they will be happy to support your loved one by supporting you.

Keep your list in a notebook or on your computer or electronic planner so it's easy to find and add to. If you are extremely lucky you will have one or two people who are all three - D, L and C! Just try not to 'burn out' any one person. If they can support you in more than one category, it's easy to do. You are in this for the long haul and need 'D', 'L' and 'C' support long term.

I am finding that those of us actively involved in caregiving truly CARE for each other as well as our loved one. Sometimes helping someone else is a stress relief for me! Be open to new friendships with those you meet through various support groups, such as the Lincoln Alzheimer Association Early Onset Support Group that meets twice a month and has activities periodically.

Don't forget the Alzheimer's Association 24/7 Helpline, 1-800-272-3900, or info@alz.org as someone to 'Listen' but also provides helpful suggestions. I prefer the phone if I have immediate issues involving my loved one and want to know how to handle something that's going on right now. They have trained personnel to whom you can speak. Even if you have a great local counselor or psychologist you are working with, the local professionals aren't generally available 24/7. If you are looking for something that is not so immediate, the email address is a good bet.

As more and younger people develop Alzheimer's and other dementias, more and more of us are becoming caregivers for spouses. An excellent resource for spouses is a site begun by and for the spouse of a person with early onset Alzheimer's.

The website is www.thealzheimerspouse.com. There are a plethora of resources available through this site, and the topics applicable for any dementia:

- A daily blog by Joan Gershman, the site's founder
- A message board where NO question or discussion topic is off limits
- Information on available products, books and other resources of help to the caregiver or for the person with the condition
- Links to articles, videos, and radio broadcasts of interest on the topics of Alzheimer's and dementia in general
- Caregiver Tips, Financial Information, Humor (gotta laugh or you'll cry), Memory Techniques
- And SOOOOO much more.

If you don't have your own computer, this site is so valuable it's worth making a trip to the library or a friend's house to use a computer. This site is so good it's worth taking a class to learn how to use a computer so you can benefit from all this site has to offer.

I hope you find these few suggestions and resources as useful as I have. Watch this newsletter next quarter for more hints on finding support for yourself and your loved one.

LIVING in an Evil Fog

By David & Elizabeth (Betsy) Howe



My family and friends ask how I am doing. The answer usually is ‘fine.’ I think I am doing fine overall. Very few ask what this condition feels like. It feels like living in an evil fog.

A fog is something all can understand. ‘I’ am inside. I can see out. I ‘know’ who I am and what I should be able to do. I ‘know’ what I want to say. But the fog envelops me. It holds me in its evil grasp. It keeps me from doing all I know I can. It keeps me from doing all I know I could before.

The fog is like a demon from a horror movie. It pulls me deeper and deeper into itself. It pulls me farther and farther away from my ‘outside’ life. It makes my body less responsive and capable. It keeps my thoughts inside and won’t let me send them out to the world.

The fog never goes away. The fog just sucks me in deeper and deeper, day by day, farther and farther from what should be my life. It’s hard to watch myself leaving. It’s hard for my wife and family to watch me leaving. I know that. I see that.

My wife and I do not dwell on what is gone. We focus on what is left. Much is left. It is comforting to have great friends and family who care. Our friends continue to socialize with us, even though I get quieter and quieter. The right words more often won’t come out of the fog. The fog grabs my ideas as they form and pulls them back into its evil clutches. By then the conversation has moved on without me.

The fog slows time for me and speeds up the outside world. Everything seems to move faster. I seem to keep moving slower. I daily trudge through a fog as thick as molasses. It sometimes gets exhausting and I must take a break with ‘no brain’ things like reading or watching TV, but every now and then even reading or watching TV is exhausting.

Sound depressing? My wife and I are doing great at accepting and not being depressed. ‘What is’ is ‘what is.’ I cannot change it. No one can change it. My wife helps me continue to be ‘me.’ She helped me put together this article to share with you.

I hope that as the fog grows denser and pulls me farther and farther away, my friends and family will remember ‘me.’ I hope they will treat me like they say you should a coma patient. I hope they will continue to talk to ‘me’ even when they can no longer see the ‘me’ clutched deep within the fog.