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A Caregiver's Guide to Advanced Dementia

Compassionate Evidenced-based Care
for the End-stage Demented Patient

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Foreword

The first question I need to ask the reader is, “How much do you want to know?” I ask this question with great sincerity as medical evidence and personal experience show that some patients and caregivers do not want to hear the whole story. The truth, for these people, is too emotional and they might prefer to not read what I am about to write. If you are one of them, please return this guide to whoever gave it to you and defer the discussion of the care for your loved one to your doctor or perhaps a different family member or friend. For the rest of you, please read on.

Caring for an end-stage demented loved one is an emotional, physical and financial challenge. The burdens of this experience can leave a caregiver feeling overwhelmed with issues of guilt, doubt and isolation. It is so overwhelming that 72% of caregivers report feeling relieved when their loved one finally dies. The problem is that many of the decisions surrounding the care of the demented are a choice between two, or more, difficult pathways. Furthermore, guidance from the healthcare industry has been weak. The time and expense in managing these patients can also be immense.

This guide cannot remove all of the difficulty in caring for your demented loved one but will hopefully make it easier to understand and prepare for the inevitable changes you will see in your family member or experience yourself. As well, it may help you to avoid making decisions that are counterproductive and even harmful.

I would offer you some of the best advice ever given to me by one of my patient's caregivers who was involved in the care of her second demented loved one. I simply asked her how it was that she handled the stress of her caregiver role so well. Her response – “Any time something catastrophic happens I just deal with it and get over it as fast as possible, because something new and catastrophic is right around the corner.”

Introduction

The estimated number of Americans currently with dementia is 5.1 million. By 2050 it will be 13.2 million. The reasons for the increase in dementia have to do with our aging population, decreased death rates (mortality rates) from other diseases and an increased awareness that dementia is a deadly disease.

The probability of developing dementia is 19% between the ages of 75-84. Over the age of 85, the probability is 30-50%. These are the fastest growing segments of our population. This is partly due to the fact that diseases such as cancer and heart disease are either being cured or managed with much greater efficiency such that patients are dying from other causes.

Adding to the increased awareness of dementia is that healthcare providers are starting to acknowledge the aggressive and deadly nature of this disease. Historically this has not been the case. In a study looking at demented patients admitted to nursing homes in New York State between 1994 and 1997, of 1609 patients studied, only 1.1% of physicians provided evidence or documentation that they knew the patient was terminal. Seventy-one percent (71%) died within 6 months.

It should not be surprising then that historically dementia has been under reported on death certificates. Physicians, for example might report that a patient died of respiratory failure from pneumonia. However, it was dementia that precipitated the respiratory failure.

Life expectancy in dementia is reported on average between 5 to 9.3 years. These numbers are probably overestimates when we account for rapidly progressive disease. Regardless, caregivers should be aware that the range of life expectancy is 1 to about 15 years. Caregivers should prepare that they may be in for a rapid or very long process.

Definition

So what is dementia? A simple definition of dementia would be a decline in mental function that interferes with a person's memory and ability to interact normally.

The technical definition of dementia is the following – both are required.

- A) A decline in two of the following four categories
 - a. Memory
 - b. Ability to generate coherent speech and understand written and spoken language
 - c. Capacity to plan, make sound judgments and carry out complex tasks
 - d. Ability to process and interpret visual information
- B) Decline must be severe enough to interfere with day to day life

These definitions are unfortunate however, because it is clear that dementia also involves physical and physiologic deterioration.

There are several types of dementia. Alzheimer's dementia is the most common. Dementia is rarely reversible and a physician can easily do a work-up to determine if that is the case. Sometimes but not always, it is important to know what type of dementia your loved one has, as this could effect treatment and prognosis. It should be recognized however, that dementia, when not reversible, is a uniformly fatal disease. It is unfortunate that healthcare providers frequently refer to medical treatments as "curative care". Care provided to any patient with a chronic medical condition is rarely curative. Medical research has shown that 27% of patients die believing the healthcare industry failed them because their condition should have been cured even when it was an incurable disease. Dementia is an incurable disease.

It is also critical that a caregiver be aware that dementia will manifest in several other areas of decline besides the mental deficit. The areas of decline which will occur in the patient are functional (physical ability) and physiologic. Physiologic changes are seen in the latest stages of



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dementia. Some physiologic changes will be seen on blood tests. However, they are not always present.

Dementia Has Many Faces

Caregivers should be aware that most patients will not reach the end-stages of each area prior to passing. As well, each demented patient may deteriorate at a different rate in each area. For example, some demented patients will completely lose the ability to communicate but will still be able to assist with physical activities. Others will lose functional ability but retain some ability to speak.

Be Prepared – Many demented patients will become angry, or verbally or physically violent. Family members may be misinterpreted as enemies or behaviors by the caregiver may be perceived as a threat. Take appropriate precautions but also be aware that this is a consequence of the disease. Try not to take the behavior personally – the patient cannot help themselves. Seek the advice of your physician or professional if this behavior occurs.

Mental decline may begin as short term memory loss or forgetfulness, progressing to the inability to perform complex and then simple tasks. It may start as the inability to prepare food, pay bills or use the phone. Demented patients will eventually lose the ability to recognize loved ones and may develop limited or no speaking ability. The Folstein Mini-mental status exam is commonly used by your physician to assess mental decline.

Physical decline will manifest in the inability to perform what are termed ADLs – the activities of daily living. The ADLs are bathing, grooming, dressing, toileting, transferring and feeding. Bathing is usually the first to go. Feeding is usually the last to go. Most patients will become incontinent of urine and stool – **be prepared**. I have heard many stories of the patient and caregiver being out at their favorite restaurant only to be embarrassed by an “accident.” Understand that loss of bowel and bladder control is expected. Your physician should be advised of the change but it is not a medical emergency.

Caregivers and families need to prepare for when the patient can no longer ambulate or assist in their ADLs.

In the latest stages of dementia a patient will lose the ability to swallow. When a patient loses the ability to swallow they are at high risk for developing pneumonia. It can be a very poor prognostic marker. Choking and coughing while feeding is expected. The Functional Assessment and Staging Tool (FAST) may be used to evaluate a patient's physical decline.

Physiologic decline may manifest as delirium, bed sores, irreversible weight loss or recurrent infections. Eventually there will be nothing that can be done to fight off an infection including state-of-the-art antibiotics. The most common cause of death in demented patients is pneumonia. Anemia and low blood albumin (an important blood protein) may also occur and are frequently not reversible. Low blood albumin is associated with markedly increased rates of death from surgery, infections, poor wound healing, and prolonged hospitalizations. Albumin can be used as a prognostic marker of a patient's overall health and short term prognosis.

I have heard comments that dementia is like raising a child. In some ways that is true. In others it is drastically different. One of the most important comments I can make is that unlike a child, your demented family member will not get better with repetition or education. As well, the change is loss, not gain, of memory and ability over time. This can make it very difficult, as it is hard for some family to let go of the memory of their loved one from years past. Family members will futilely keep trying to turn back the clock with efforts to help the patient remember. This can be remarkably frustrating. In the early stages of Alzheimer's and Lewy Body dementia there are medicines which may help slow or very temporarily reverse this process. Dementia however, is a disease that takes away brain function and does not return it. The sooner a caregiver accepts this, the better they can deal with the inevitable decline. For point of information, short term memory is usually the first to go. Long term memory may last for years.

The bottom line is that over time it gets harder to care for the demented patient, not easier.

Areas of Caregiver Concern

There are two other areas that a caregiver should be aware of when caring for a demented loved one. These are the financial decline and caregiver burden.

The comprehensive cost of dementia in this country is estimated at \$148 billion annually. It is estimated that \$36.5 billion dollars are lost by caregivers who lose or quit work to care for their loved one. Eight point three (\$8.3) billion dollars is the estimated cost of the work done by unpaid caregivers.

Whether you are a caregiver who wishes to continue to work, or not, there are places you can go for help. Here are a few examples with estimated costs. Prices will vary dramatically depending upon where you live: home health aides - \$19/hr, homemaker or companion services - \$17/hr, adult day care - \$56/day, assisted living - \$2986/month, custodial nursing home- up to \$75,190/year.

The financial burden to the caregiver, as well as the patient, is clearly an issue.

As well, caregivers deal with emotional and physical strain. Family members should be aware that choosing one member to be in charge of the care of the demented patient can be hazardous and overwhelming to the chosen caregiver. Family members who are not directly involved with the care of the patient can have devastating effects on the caregiver if they do not appreciate the tremendous burden of care giving. One in four caregivers will work over 40 hours per week for up to five years or more. Regardless, most caregivers will tell me that emotionally they worry about the patient 24 hours a day, seven days a week.

The emotional and physical burdens to the caregiver are not without consequence. Caregivers suffer a multitude of issues which should be respected by family and healthcare providers. These include but are not limited to loss of promotions, work and health care benefits, severe insomnia, depression and anxiety disorders. Medical research has even confirmed that stressed caregivers are at increased risk of cancer and premature death.

Many caregivers will have promised their loved one that they would never place them in a long term care facility. The reality is that most caregivers had no idea how difficult it would be to care for a demented patient when making that promise. Caregivers should not feel guilty if they are unable to burden the stress of caring for their loved one. My professional experience, in fact, is that in many cases the caregivers do better caring for their loved one when they are relieved of the custodial burdens. Placing a family member is never easy – this is the choice between the lesser of two difficult pathways.

Statistically 70% of patients with dementia end up in long term care facilities.

The bottom line is that dementia is a disease of the family and should be treated as such.

Where can you go for additional Help?

There are, however, several places families can look for help prior to or instead of placing a demented patient in a nursing home or assisted living facility. Local support groups such as the Alzheimer's association can provide emotional support and other references.

Respite Care: Respite care is custodial care provided to the patient for the well-being of the caregiver. There are two common sources of Respite Care: 1) Medicare supplemental insurance such as Secure Horizons or 2) Hospice Care when a patient is on Hospice.

Understanding the Difference between Custodial Home Health Aide Care and Home Health Nursing Is Critical

It is an area of tremendous confusion and can precipitate unnecessary anger. As well, it can be financially devastating when a family does not know how to properly access these services or gets stuck with a bill they thought would be covered by their insurance. Custodial care helps patients when they are deficient with ADLs. Custodial care is delivered by **home health aides**. Home health aide care is not covered as a part of routine care on any health insurance plan, including Medicare and Medicare supplemental insurances, that I am aware except through Respite Care. **Home health nursing** is covered for higher levels of skilled need such as home IV medication management or recovery from a stroke. Home health nursing is usually for only a few days to a few weeks after acute hospitalization.

One of the harshest experiences patients and families undergo in this country is the fact that custodial care is not covered as a part of their standard health insurance. Historically this has had devastating consequences. For example, at one point, almost half the geriatric women living in poverty in this country had never lived in poverty until they lost the family life savings caring for the custodial needs of their dying husbands. (Men usually die first)

So how can a family access Respite services through their health plan? To access these services call your plan **directly**. **Respite care is administered by the insurance plan and not your doctor's office or medical group**. Your doctor can work as an advocate for you once you have obtained the proper forms from your health plan if necessary. If your insurance offers the benefit **be prepared** that the benefit is usually limited. For example, Secure Horizons may offer 80 to 120 hours per year. This however, is better than nothing and may provide one day a month to get out of the house and take care of personal needs.

Be Prepared

Be prepared as well, that your insurance representatives may not understand their own plans. I have personally encountered, on multiple occasions, representatives who could not tell the difference between home health aides, respite care and home health nursing. Ask for a supervisor immediately if the representative you speak to does not appear informed and always ask for their full name or identification. If your representative tells you, "All you have to do is get your doctor to write a note authorizing it," get their full name and time of call. **THIS STATEMENT IS NOT TRUE** and you may find yourself in a complicated situation. In most cases this statement will simply mean that the representative does not understand the plan's benefits.

Do not ask your doctor to call Home Health Nursing if you are on Medicare. It is Medicare fraud for your physician to request Home Health services if the patient does not have a Medicare Part A skilled need. The penalties for fraud are severe.

The best prepared families get the best benefits. Custodial care can wipe out a family's life savings. Statistically 1/3 of American families lose most or all of their life savings caring for a loved one at the end-of-life. As well, as stated earlier, historically about half of geriatric women living in poverty were never in poverty throughout their lifetimes. The reason this occurs is because most families do not understand that the Government's Medicaid program (Medical in California) does not assist families until they are impoverished and Medicare (Care for people over 65) only pays for hospitalization and doctors services. Custodial care is up to you. Trying to hide or give away your assets improperly puts the patient and family in double jeopardy. The best way to legally protect a lifetime of assets and hard work is to consult specifically with a qualified Medicaid attorney. Medicaid regulations are constantly changing but I would advise you that the current window to protect assets requires that you transferred them 36 months prior to asking for Medicaid assistance.

When a patient is in the end stages of their dementia and they are at home on hospice, families can access respite benefits once for each certification period. This is usually 5 days in a nursing home under custodial care.

In Home Support Services (IHSS)

If a patient is on Medicaid, the caregiver may qualify for in home support services or even be paid to care for the demented patient. Contact your local Medical office to see if you qualify. Not all states pay for in home support services.

Long-term care insurance: Once a patient has ADL deficit they may qualify to use their long term care insurance. For many patients this is an excellent time to access that benefit. Long term care insurance may provide the opportunity for a patient to stay at home. Even if a plan only offers a defined or limited benefit, it may be better to use that service sooner than later, since when a patient progresses to the later stages of disease they may lose the ability to appreciate their environment.

Sharp HospiceCare is now offering a state-of-the art program to assist families with the difficult issues of understanding and managing a later stage demented patient. The program will provide in-home or nursing home assistance and education by a registered nurse, physician, social worker and chaplain. The name of the program is *Transitions Dementia*. This program however, is currently only covered if you are a part of an HMO contracted with Sharp Rees-Stealy or Sharp Community Medical Group. Families can pay out-of-pocket for the service as well. It should be understood that this program can be initiated long before a patient would qualify for Hospice and that there are no restrictions on the care provided. To contact Sharp HospiceCare call 1-619-667-1900.

End-of-Life Issues

Despite valiant efforts by many families, most patients with dementia end up in a long term care facility. The family will be asked to fill out an advanced directive if the patient does not already have one. However, even if a patient has one, it may be of value to review it in the context of what you are about to read, as my experience is that patients and families are poorly informed prior to deciding specific treatment choices. Before filling out this form the family and patient, if possible, need to be clear on the **priority of care**. The health care industry has opted to err on the side of prolonging life at all cost with quality-of-life as a secondary issue. Yet in studies of geriatric patients asked where their priorities lie, 88% say quality-of-life is more important than longevity. It is critical that you and your loved one decide what the goals of care are and to express that to your attending physician and nursing home staff. Here are some important pieces of information relating to that form.

Resuscitation/Code Status

It has been reported that the probability of surviving a true cardiac arrest in a nursing home “approaches zero percent”. Most studies I have read report survival between 0 and 2%. The most optimistic studies put the probability of survival at 5% but are of questionable quality. Television and the media may participate in misguiding the public in the true value of CPR.

However, this is not the whole story. For years the health care industry has had a difficult time giving patients and families full disclosure. By not providing full disclosure we create unrealistic expectations and decisions may be made that are otherwise misdirected. Patients and families may be left to believe that surviving resuscitation means that you go back to the way you were before. This is not always true. Survival statistics as they are reported to the public simply means that the patient survived to be discharged from the hospital. It has no bearing on the quality-of-life.

Many patients who survive a cardiopulmonary arrest suffer severe hypoxic (lack of oxygen) brain damage. Terri Schaivo, for example, would be reported to the public as a resuscitation success. It is wonderful when a patient survives a code and they or their family are happy with the result. It can be devastating when the result is suboptimal. As harsh as it may seem, I have personally been told by families that “it would have been better if my (loved one) had just died.” I have also cared for patients who suffer extreme depression for the state they are left in. I would not suggest that we should stop providing CPR to those who request it but it is unethical to mislead families and patients by withholding information and misrepresentation. In fact, it is interesting that even in the studies which report more optimistic chances of survival, the vast majority of patients who survive a cardiopulmonary arrest, switch to DNR so that they don't have to undergo the experience again.

Equally problematic is that DNR (do not resuscitate) is incorrectly interpreted by patients, families and even healthcare providers to mean, do not treat aggressively. This is not true. DNR simply means that if a patient has an arrest they will be permitted to die a natural death. If hospice is involved, the probability of that death being dignified and painless markedly



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increases. DNR status should have no bearing on other treatment options. This, in fact, is the position of the AMA's Council of Judicial and Ethical Affairs.

Nutrition – Feeding Tubes

It may seem intuitive, that if a demented patient loses their appetite or starts to lose weight that we should try to reverse the process. This may not be true in most cases. Decreased appetite and weight loss at the end-of-life are common and may in fact be adaptive. An appropriate work-up should be done looking for reversible causes of these changes guided by the priority of care. However, frequently no cause is found.

There is currently no term in medical language which describes this process. **These patients are not starving.** Starvation implies withholding food from people who would otherwise want to eat. Many of these patients are eating normally and others when offered food, do not accept it. This is not fasting. Fasting is a voluntary act. This process is not voluntary. Dieting is also a voluntary act and has no meaning in this context. Some physicians might use the word anorexia – the loss of appetite. This is not loss of appetite. It is diminished ability to process food due to underlying physiologic changes as the body prepares for end-of-life. As well, for two other reasons anorexia is not a good term: anorexia implies something that we should try to reverse and carries negative cultural and social connotations that do not apply to demented patients.

The best phrase we can use is that these patients are in a new metabolic homeostasis – balance. There are several issues which appear to be occurring here. The first is that the patient's metabolic needs are decreasing. As patients age we know that their basal metabolic caloric utilization drops. As well, their activity drops. For non-ambulatory patients daily caloric expenditure may drop to as low as 900 calories per day. This may scare some families, especially when the average American is estimated to eat 3900 calories per day.

Lastly, there is the emerging concept of **frailty**. Frailty is a metabolic process mediated by chemical changes in the body. My best explanation is to think of it as a process similar to puberty or menopause. We clearly do not understand this process as well yet as puberty or menopause but we understand the effects. For one, we can try to force feed patients who decrease their oral intake but the consequences can be devastating. Here is one example.

Historically, efforts to reverse weight loss have included feeding tubes. Feeding tubes in demented patients, however, have actually been found to be associated with **increased** rates of pneumonia, bed sores, and accelerated death, and do not improve the patient's comfort or functional status. Nor have they been found to improve the biochemical markers of malnutrition over hand feeding. Feeding tubes are also associated with a high use of physical restraints. Even before we knew that feeding tubes were detrimental to demented patients in this state, many of the minority of patients who said they would accept a feeding tube if they were mentally impaired opted against it when they were informed that they would likely be restrained.

Be aware that the use of feeding tubes in demented patients is associated with an extremely high mortality rate. This is likely both because the feeding tubes increase so many problems but also because weight loss signals the patient is nearing the final stage of life. Death rates for demented patients who receive feeding tubes are 54% at one month and 90% at one year.

So why do you see patients with feeding tubes in the nursing home? Many patients have feeding tubes for other reasons. As well, historically some physicians are unaware that feeding tubes appear to be contraindicated in this group. Lastly, one out of ten demented patients who chose a feeding tube would live past a year in spite of the fact that their risk of complications and death was increased.

There are only two arguments for the use of feeding tubes in demented patients. The first is that none of the studies evaluating the use of feeding tubes in the demented are randomized control trials (RCTs). RCTs are the best types of studies to determine if a result is valid. Unfortunately, RCTs will likely never be done in this population as it would not pass ethical standards for testing. However, the numbers of other studies looking at this information is so vast that it would be highly unlikely that a RCT would reverse these results. Other questions do not need RCTs. Such as, "do feeding tubes prevent pneumonia or bed sores?" They absolutely do not.

The other issue is cultural. Feeding has tremendous cultural meaning to patients and families. We can and should have respect for the life experience of patients who for example, survived the Great Depression, the Holocaust or have been victimized by historically unequal medical care.

Religion may also play a role. The thought of withholding food to these people can be profoundly unethical. Consideration, in rare circumstances, to families who do not accept the medical evidence, might occur.

Some physicians argue, however, that feeding tubes are so clearly contraindicated they should not even be offered.

There are many ways that your physician can help stimulate the natural appetite of your loved one without over treating them. Pain and depression management are critical. Some appetite stimulants, such as Megace, should be used with great caution and may be contraindicated in this group due to side effects such as blood clots, hypocortisolism and no evidence they improve outcomes. Hand feeding and socialization by family help.

Making foods more palatable with salt, sugar and fats may also be beneficial. The elderly tend to lose their ability to appreciate tastes. However, this may be tricky if your loved one has other illness such as congestive heart failure, renal failure or diabetes.

Be aware that diminished appetite is **common and expected** in end-stage dementia. It may be difficult to watch. It is fair to ask your physician to do everything they should to stimulate your loved ones appetite safely. However, many treatments may be counterproductive whether the goal is quality-of-life or longevity. Never ask your doctor to “just do something”. It can make a difficult situation worse. In fact, this concept should be applied to all requests. Unfortunately, not “doing something” to some family will seem like not caring. This is not the case. Learn the difference between doing everything that should and everything that could be done.

Hydration

What about hydration?

Encouraging oral fluids is appropriate so long as they are not forced. The medical evidence against forced hydration is similar to solid nutrition although the research is not as vast. However, IV therapy (intravenous fluids) has no place in the long-term nutrition of any patient as IV fluids provide vitamins, sugar and electrolytes but no other nutritional value. Patients cannot survive without protein and fats.

Relative dehydration as well, may be adaptive, decreasing and thickening oral secretions so they are not aspirated. Excessive hydration has been associated with choking, coughing and edema (swelling), and dilutes important protective biomarkers such as albumin.

Be aware that over-hydrating a demented patient lowers their serum albumin level. Evidenced-based medicine shows that the lower the albumin the higher the mortality rate (death rate). There is also a direct relationship with lower albumin levels and increased rates of bed sores, prolonged hospitalizations and infections.

This does not mean that your physician should never use IV fluids. Temporary use for acute illness is occasionally appropriate. As well, IVF may temporarily reverse delirium in some cases.

There is no evidence that IV fluids decrease suffering at the end-of-life and appear to increase pain and discomfort. They do so by interfering with the process of end-stage ketosis. As a person approaches the end -of-life the decrease in food and liquid consumption trigger a biochemical process known as ketosis. The body turns to fats for fuel. This process causes chemical changes which cause analgesia, anorexia and euphoria – all processes that decrease suffering.



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Terminal Delirium

Terminal delirium is also known to occur in up to 80% of patients. It is a common final pathway as death approaches. Terminal delirium is argued to be emotionally protective as the patient can no longer appreciate they are dying. Reversing delirium with fluids may simply return the patient's awareness that they are dying, therefore increasing their emotional suffering.

End of Life Observations

Decades of observations by end-of-life nurses and physicians support that ketosis from decreased solid and fluid intake occurs. As well, various methods of inducing ketosis in animals have been associated with the release of the body's natural morphine – endorphins and dynorphin. Ketones, as well, have been found to have direct analgesic effect.

We have seen the benefits of ketosis in other areas. Persons who fast voluntarily for religious or other reasons, state that after a day or two of complete fasting hunger and thirst subside. Euphoria then may set in. When carbohydrates are reintroduced to the person, as are found in many IV fluids, hunger and discomfort return.

Further evidence comes from patients at the end-of-life who retain the ability to communicate. Demented patients cannot tell us how they feel late in the disease process. In a study of 32 cancer patients admitted to a terminal care facility over the course of a year, 31 stated that they were not hungry or that hunger subsided rapidly. Twenty (20) said the same for thirst. In all 32 patients however, hunger or thirst could be easily managed with trivial amounts of food, sips of water, ice chips or simply a swab to the mouth. These tiny amounts of food and fluid in any other circumstance would not have relieved symptoms. Particularly interesting, is that in nine of the patients who chose to eat to satisfy the emotional needs of the family, all nine suffered indigestion and increased discomfort.

For years, families would rush a patient to the emergency room to treat their dying loved one with hydration for comfort. Ironically this may have accomplished the opposite effect. It is furthermore, understandable that the family may get mixed messages from physicians. An emergency physician might evaluate an end stage demented patient and make the misguided comment, “the patient appears dehydrated”. This is relative dehydration to a patient at an earlier and healthier stage of their life. In the current stage it may be homeostatic and a testimony to their end-stage illness. Misguided care and advice may ensue.

Other Considerations

Treating patients with pneumonia and other infections:

Depending on the patient and families priorities of care, all, some or no infections may be treated with antibiotics. Regardless, a few issues may make the decisions on how to best treat your loved one more obvious.

There is some medical evidence that antibiotics do not improve the comfort that can simply be provided by aggressive pain and symptom management. Antibiotics may only be appropriate if the goal is to prolong the patient's life. If you do not wish to treat your loved one with antibiotics then hospice may be appropriate. However, antibiotics can be used even if the patient is on hospice.

If a patient develops an infection and is cured, **be aware** that the infection will return sooner or later. The issues which permitted the infection to occur have not gone away. Demented patients have weakened immune systems, commonly aspirate oral secretions and gastric contents, are frequently bed bound and may have lost a strong cough reflex. A bed bound demented patient is at 3.4 times the risk of developing a urinary tract infection (UTI) and 6.8 times as likely to develop pneumonia as an ambulatory patient and they are already at increased risk due to their age and medical condition.

The most common cause of death in demented patients is pneumonia. Studies estimate that 30-70% of demented patients die from pneumonia. **It is not a medical error** when an end-stage demented patient dies of pneumonia, as has been implied by recent reporting; it is the natural consequence of the disease process. Eventually, even with the most aggressive treatments the body and immune system will become so weak that no treatment is effective. Multiple antibiotic resistances may also occur, complicating the picture. As the patient becomes frail, studies show that the probability of death, even with antibiotics approaches 50%.

Very Important! If the goal of care is to prolong the patient's life **be aware** that transferring a demented patient to the hospital from a nursing home for the treatment of pneumonia **has not**

been shown to decrease their acute risk of death and has been associated with an increased risk of death after 2 months. The only exception may be ambulatory demented patients with an elevated respiratory rate. As well, transferring a demented patient to the hospital is associated with increased risk of mental and physical decline versus treatment at their place of residence. The highest risk patients are those with something to lose.

Research has shown that demented patients transferred to the hospital from nursing homes for care are five times more likely to develop delirium. Delirium is mental confusion and disorientation on top of their dementia. Delirium is NOT necessarily reversible as previously thought and is associated with increased death rates.

The bottom line is that transferring a demented patient from a nursing home to the hospital for the treatment of their pneumonia appears to accelerate their death and increase their suffering.

Transferring demented patients with pneumonia to the hospital is a cultural phenomenon. Studies show that other industrialized nations transfer these patients at much lower rates. For example, one study showed that the Dutch transfer demented pneumonia patients to the hospital at a rate of less than 1%. It is perhaps unfortunate that Medicare reimburses physicians at markedly higher rates to care for demented patients in the hospital, and historically has discouraged aggressive nursing home management. Considering the fact that in the U.S. we have markedly higher per capita expenditures on our geriatric population yet some of the worst mortality statistics, further research in this area is warranted.

It is critical that just like feeding tubes, families be aware that aggressive care does not always mean ethical or effective care.

Hospitalization Results

Several issues may explain the phenomenon of increased mortality with hospitalization. These are hospital iatrogenesis, psychologic depression, stress and disorientation from involuntary relocation, and the fact that the actual medical treatment for pneumonia is no different in the nursing home than the hospital.

Hospital iatrogenesis refers to complications of hospitalization that are not a part of the disease process. Some iatrogenic complications can be minimized but not eliminated by prevention, such as good hand washing to decrease the spread of infectious disease. Some cannot be significantly minimized. Delirium (mental confusion) and functional decline are common iatrogenic complications of the frail elderly. Falls, incontinence, and exposure to unnecessary, although well intended, but contraindicated medical procedures may occur – placement of a feeding tube for example. Delirium and functional decline may occur in as much as 60-80% of the high risk frail elderly. The demented are some of the highest risk patients.

The concept of **Delirium** is worth discussing in greater detail.

Delirium is acute mental confusion. It is diagnosed by its abrupt onset, fluctuating nature, inattention, disorganized thinking and altered level of consciousness. Not all of these features are required for the diagnosis. Delirium is frequently mistaken by healthcare providers as depression or by families as other disease of the brain, such as a TIA. (Perhaps this is because delirium may present with slurred or disorganized speech.) Many times delirium is very subtle – and because of many issues including its fluctuating nature, overlap with dementia, failure to consider the diagnosis by healthcare providers, and marked under appreciation for the consequences, reports estimate it is missed by up to 70% of the time. Studies report accurate detection in the emergency room of only 35% and by inpatient physicians of only 27%.

However, there are significant issues and consequences for not recognizing delirium. For example, delirium which is induced by a hospital stay is associated with prolonged hospitalization, long term mental and physical decline, markedly higher rates of discharge institutionalization for patients who were

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not in institutions prior, markedly higher readmission rates within 30 days of discharge – 67% in one study, and dramatically higher death rates. For example, one recent study showed patients who developed delirium while in the hospital for any reason but who had no delirium prior had hospital death rates of 22%. That compares to 2% for controls. This is an 1100% increase in mortality! To put that into perspective, these mortality rates are similar to those for acute myocardial infarction (heart attack) or severe sepsis. Another study showed that prevalent delirium – delirium present before the patient is admitted to the hospital – was associated with hospital death rates of 41.9%! That is much higher than death rates from heart attacks and sepsis.

Dementia is the greatest risk factor for developing delirium when a patient is sent to the hospital. Medical research states that dementia increases the risk of developing delirium by 500%.

Because of deliriums' fluctuating nature it has historically been thought of as a transient disease. It is frequently not transient. The decrease in mental and physical ability has been shown to persist for years after the patient is discharged and the increased mortality rates after the initial event have been shown to persist at 6 months, 12 months and 2 years. Another recent research article showed that one year mortality rates for patients who developed delirium were 63.3% versus 17.4% for controls, although the effect was not as strong for patients with pre-existing dementia in this article.

Many families will recognize this experience when they note “mom was never the same after her hospitalization.” Others will recognize delirium by the night time confusion which develops in demented patients. This is called “sundowning.”

In fact, the new understanding of delirium challenges decades of medical practice. When families take frail or demented loved ones to the emergency room, the emergency room physician or attending physician might suggest that “we just watch them in the hospital for a day or two.” As we know now, whether a patient already has or develops delirium while in the hospital, that may be the worst pathway to choose. It is not malicious, but the argument that is then put forth that the admission is justified because

the patient got so sick or died should be balanced by the argument that they might not have gotten that sick if they had just been sent back to their place of residence.

The health care industry is starting to recognize the importance of delirium. However, they are currently trying to deal with the problem by addressing risk factors once the patient is in the hospital. A better way to deal with the problem may be to NOT TRANSFER the patient to the hospital in the first place or to transfer them back to their place of residence after an emergency room evaluation. This is especially true since medical evidence suggests that 60-70% of cases of delirium cannot be prevented in hospitalized patients. Many of the treatments needed to save the life of a patient are associated with a high risk for developing delirium – such as placing a Foley catheter in someone with urinary obstruction. Placement of a catheter has been found to be an independent risk factor for the development of delirium. As well, ironically, the same surgery which repaired a broken hip or body malfunction may be the final straw in inducing delirium and the patient's decline.

Ironically, “adverse events” have also been associated with the development of delirium. An adverse event can be defined as any invasive procedure or surgery. Therefore, an overly aggressive work up for the causes of delirium could cause delirium. A single dose of a single pill has been shown to cause delirium in susceptible patients. Cat Scans, MRIs, lumbar punctures, and EEGs are rarely needed in the work up for delirium.

Infections, medications and metabolic abnormalities are the most common precipitating factors for delirium. However, whether a patient develops delirium depends on their level of susceptibility. Demented patients, frail patients and especially frail demented patients are the most susceptible.

To lower a demented patient's risk of delirium it should be noted that NOT admitting a demented patient to the hospital, but treating their infection or acute illness (e.g. chest pain) in their place of residence, could provide a better outcome. Risk factors that are noted to raise a patient's chance of delirium that may be made worse by transferring them to a hospital include: unfamiliar environment, disruption of routine, sleep disruption, frequent room changes, sensory overload, sensory deprivation, prolonged ER

stay, depression, bereavement, pain, and psychosocial stress, loss of independence, immobilization and lack of social support. (These arguments may also be true for the non-demented frail elderly)

There are several models to predict whether a patient will develop delirium when admitted to the hospital. One model was able to predict the incidence of delirium 83% of the time. What is important to note is that regardless of the model, demented patients have most or all of the risk factors prior to admission! It should not be surprising that delirium is reported as “the most frequent complication of hospitalization in this population.”

The bottom line is that regardless of how difficult this fact may be to accept, medical evidence appears to show that transferring certain groups of patients to the hospital for their care, even if that care would have been appropriate for them at an earlier and healthier stage of their life, may in fact increase their chance for death and disease.

Involuntary relocation is also a concern. In studies looking at the involuntary relocation of geriatric patients who were transferred for issues other than illness, there was a 41-71% increase in mortality in the patients who were depressed or in denial about the move compared to controls. Simply relocating a demented patient may put them at risk.

Future Health Care Tenants

I would argue that one of the tenants for future health care reform will be the goal of **bringing health care to frail patients whenever possible and not bringing frail patients to healthcare.** The Sharp HospiceCare Transitions program is such an effort.

Medicare itself has not made this possible and in fact may incentivize care which unintentionally harms patients. For example, a frail patient under the current system has to go to the hospital for care (at times this is involuntary relocation), and must stay in the hospital for three days before they can be transferred to a nursing home for further care. Frequently, three days in the hospital are not necessary before a patient could be transferred. Hospital iatrogenesis such as delirium occurs as early as day two.

Here is another example. Historically, CMS – Medicare's advisory and management committee, would put out report cards on weight loss in nursing homes. Nursing homes subsequently encouraged feeding tubes to show CMS that "aggressive measures" to reverse the process were offered. Medicare will furthermore pay a nursing home higher rates to participate in tube feeding than to encourage what is medically proper – hand feeding. Hand feeding is time consuming but Medicare considered it not procedurally oriented so they do not increase reimbursement for this effort. It took many years before Medicare partially rectified their serious mistake.

Ethical Dilemma: Before proceeding with why hospitalization of a demented patient may increase death and disease I would like to discuss a serious ethical issue which arises in the care of demented patients. The caregiver stress and burden, as discussed, is not without risk. Medical evidence shows stressed caregivers have a 63% increased mortality rate compared to controls. Medical evidence also shows that involuntary relocation of depressed patients have a 41% increased mortality rate compared to controls. Social or spiritual support, psychotherapy and medicines can help either patient or caregiver to some degree. So should the caregiver leave their demented loved one in the nursing home or not? This is simply another example where the answer is an individual choice between two difficult pathways. Evidence-based medicine shows

that the use of Hospice care early decreases the absolute risk of death of the caregiver by 0.5%, one out of every 200 Hospice referrals.

Other evidence supporting treatment of a demented patient in their place of residence whenever possible includes research showing that increased physician presence in the SNF, physician extenders or the use of Hospice services have all been associated with about a 50% reduction in hospitalizations for nursing home residents. Yet mortality rates in these circumstances do not rise. In fact, in a review of Medicare death certificates from 1999 to 2000 demented patients who were provided Hospice over non-hospice care at the end-of-life lived longer on average by 45 days.

Do Not Transfer to Hospital

This is one of the most underutilized yet ethical and appropriate orders in the nursing home. Caregivers have the right to request this order. As with DNR it does not mean “do not treat aggressively”, whether that is life-prolonging or aggressive comfort care. Families should be aware that nursing homes have an obligation and tendency to transfer patients to the hospital unless this order is written. In studies where families were aggressively educated about the issues of end-stage dementia, do-not-hospitalize orders increased from the usual 2-4% to 62%.

Some families will want their loved one transferred to the hospital for comfort reasons. However, medical evidence has shown that **the delivery of comfort care in the hospital is abysmal**. Even within days to hours of a patient's death in the hospital research has shown that 40-50% of patients were still suffering from severe pain. This should not be surprising, as the goals of care in the majority of hospitals are curative or life-prolonging. If your priority is simply to make your loved one comfortable, than in most cases there is no clear reason to ever transfer them to the hospital. Get the patient on Hospice as soon as possible. Ninety percent (90%) of families and healthcare providers believe that at some point palliative and Hospice care are appropriate for the demented patient. This order can be proactively written as well. “Place patient on Hospice as soon as they qualify.”

Some families will prefer to continue hospitalization in all or some circumstances. This is acceptable. However, families should be aware of the mortality associated with more aggressive procedures in demented patients. For example, the 6 month mortality rate for repairing a hip fracture in a demented patient is 55%. That is over 400% higher than for other elderly. The same statistics exist for treating demented patients with pneumonia with the added increase in 2 month mortality if the patient is transferred from the SNF to the hospital. It can be argued that it is not the surgery or the event, but the stress of the surgery, which precipitates their death. Does this mean we should never repair the hip of a demented patient? No. Ambulatory demented patients may benefit from a hip repair even if for only a short period of time. As well, the repair may reduce pain. However, it is also acceptable not to repair the hip if the patient is not ambulatory

or is not in significant pain. As well, families should not be surprised if the surgery precipitates a rapid decline.

Other surgeries and procedures should be evaluated cautiously. For example, a breast cancer is usually not painful in the early stages and may take years before it is a concern. Breast cancers can grow to the point where they ulcerate which is frequently more distressing to the family than the patient or cause pain due to metastatic disease. However, most demented patients will die before this happens. As well, traditional cardiac procedures may not be better than aggressive medical management. Again, proceeding with surgery or overly aggressive procedures could accelerate demise and impose unnecessary suffering.

I can only express how many times I have cared for the family of a demented patient who went for a surgery or procedure and were surprised at the common event of physical and mental decline afterwards, or rapid progression to death even if the patient was previously ambulatory or communicative. Demented patients, and families, should feel fortunate if this does not happen to them.

Prognostication with Dementia

It can be difficult to prognosticate for demented patients. **Be prepared** – Many patients will suddenly and rapidly decline before they have reached the end stages of their mental, physical or physiologic curves. However, when they do reach certain landmarks prognostication is possible. All healthcare providers and families should be aware that physicians and families have historically been markedly overly optimistic when it comes to prognosticating for terminal patients. If the priority of care is palliative, however, not qualifying for Hospice care should not interfere with this approach. Ask your physician if they are aware of how to qualify a patient for hospice if this is ultimately your goal. Sharp HospiceCare's Transitions program would be beneficial in these cases.

It is truly unfortunate that death frequently surprises the family or caregivers of a demented patient. Death is always difficult, but being unprepared only makes it worse. Part of the reason for this unpreparedness is that we tend to think of dementia as just a mental disease – it is not. Dementia is also physical and physiologic. In other words, demented patients may be quite verbal or functional prior to their demise. Here, however, are some evidence based statistics regarding mortality rates in last stage dementia. For perspective, these events hold a worse prognosis for dementia patients than death rates for end stage heart disease or many inoperable cancers.

Pneumonia – 53% at 6 month

Hip fracture and repair – 55% at 6 months

Albumin less than 3.5gm/dl (nursing home patients) – 50% at one year

Significant weight/appetite loss (which historically precipitated a feeding tube) – 54% at one month or 90% at one year

Other poor prognostic signs are recurrent infections of any type, bed sores, or any inflammatory process.

I credit my colleague with teaching me to offer these compassionate words when any of the above occur, “It may be time to take your loved one home, make them as comfortable as possible and cherish them for the little time they have left.”

Hospice Care

There are multiple benefits to Hospice Care for the demented. Hospice can be provided in the nursing home, at home or in the hospital. Some of the reasons to use hospice are evidenced-based improvement in end-of-life care (98.2% of families report satisfaction with end-of life care when Hospice is involved); markedly better pain control; fewer invasive treatments; fewer hospitalizations; decreased behavior problems in the demented patient; decreased grief, self-doubt, guilt and suffering in the caregivers; markedly improved advanced health care planning; markedly improved support for the family post-death; and increased satisfaction, empathy and caring by nursing home staff in the care they provide.

Some nursing homes will claim they can provide this care without hospice. **Medical evidence does not support that claim.** At times this suggestion by nursing home staff may be well intended. At other times it may be financially motivated.



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Prologue

I compliment you if you have made it to the end of this guide. The information can be sobering. Yet understanding the available treatments and the natural pathway of dementia can also let families know they are doing everything they should. Unrealistic expectations are a great cause of pain and suffering. I hope this guide has served as an honest tool of enlightenment and will help you with this difficult journey. Please share any concerns with your physician and healthcare providers.

— Daniel R. Hoefler MD



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Phone Numbers for Reference:

Sharp HospiceCare619-667-1900
Sharp HospiceCare toll free.....800-681-9188
In Home Support Services (IHSS)
 Aging and Independent Services800-510-2020 & follow prompts
Secure Horizons Respite Care, Members Only
 Call Lana Barney, Member Services858-658-8536
Alzheimer's Association.....858-492-4400
Alzheimer's Association Help Line.....800-272-3900 (available 24/7)

FUNCTIONAL ASSESSMENT STAGING SCALE (FASS)

SCORE	DESCRIPTION
1	No difficulty either subjectively or objectively
2	Complains of forgetting location of objects. Subjective work difficulties
3	Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organization capacity.
4	Decreased ability to perform complex tasks such as: <ul style="list-style-type: none"> ♦ Planning dinner for guests ♦ Handling personal finances (e.g. forgetting to pay bills) ♦ Difficulty shopping, etc.
5	Requires assistance in choosing proper clothing to wear for the day, season, or occasion. Repeatedly, observed wearing the same clothing, unless supervised.
6	*Improperly putting on clothes without assistance or cueing (e.g. shoes on wrong feet, day clothes over night clothes, difficulty buttoning) Unable to bathe properly (e.g. difficulty adjusting bath water temperature) Unable to handle mechanics of toileting (e.g. forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue) *Urinary incontinence – intermittent or constant *Fecal incontinence – intermittent or constant
7	*Limited ability to speak ± 6 intelligible words in an average day or interview *Speech ability is limited to the use of a single intelligible word in a normal interaction – demonstrates repetitive actions. *Ambulatory ability is lost (cannot walk without personal assistance) *Cannot sit up without assistance *Individual falls over if no lateral arm rests on chair *Loss of ability to smile *Loss of ability to hold up head independently

PALLIATIVE PERFORMANCE SCALE

(Adapted Karnofsky)

FOR ALL PATIENTS: Circle as Appropriate

%	Ambulation ①	Activity & Evidence of Disease ②	Self Care ③	Intake ④	Conscious Level ⑤
100	Full	Normal Activity, No Evidence of Disease	Full	Normal	Full
90	Full	Normal Activity, Some Evidence of Disease	Full	Normal	Full
80	Full	Normal Activity with Effort, Evidence of Disease	Full	Normal or Reduced	Full
70	Reduced	Unable to do normal work	Full	Normal or Reduced	Full
60	Reduced	Unable for most activities, Significant Disease	Occasional Assistance	Normal or Reduced	Full
50	Mainly Chair	Minimal Activity, Extensive Disease	Considerable Assistance	Normal or Reduced	Full ± Confusion
40	Mainly Bed	As Above	Mainly Assisted	Normal or Reduced	Full or Drowsy ± Confusion
30	Bed Bound	As Above	Total Care	Reduced	Full or Drowsy ± Confusion
20	Moribund	As Above	Total Care	Sips	Full or Drowsy ± Confusion
10	Moribund	As Above	Total Care	Mouth Care Only	Drowsy or Coma
0	Death	0	0	0	0
Rate					

Average score must be less than 50.

Determine score for each of the five categories.

Total the score.

Divide by 5.

Example:

① = 50

② = 40

③ = 40

④ = 20

⑤ = 50

Total

200

Self-Care Guidelines

1. Strive for imperfection – What I mean is to free yourself from the need to be perfect. Take the pressure off yourself, and relax.
2. Allow yourself to make mistakes.
3. Remind yourself of your successes, not your mistakes (although we certainly want to learn from them.)
4. Create an awareness of over caring and its impact in your life. Once an awareness is present, the process of change can begin.
5. Explore losses in your life which you have not dealt with yet.
6. Work on unfinished family of origin issues. Attempt to understand how experiences in your childhood may be impacting your need to take care of other people.
7. Discover the spiritual part of yourself. Spend alone time focusing on self-understanding and self-love.
8. Develop ways of caring for yourself.
 - a) Massages, healing touch, Reiki
 - b) Spiritual growth weekend, a retreat in nature
 - c) Go for a drive with no particular destination in mind. Slow down, observe what you see.
 - d) Treat yourself to a night in a hotel.
 - e) Visit a museum or the zoo.
 - f) Take the afternoon off and go to the movies.
 - g) Go to a garage sale.
 - h) Watch cartoons.
 - i) Visit a farmer's market and buy fresh produce.
 - j) Go dancing.
 - k) Rediscover your inner child and go play.
 - l) Develop a good support system.

Work Smart, Not Hard

1. Create specific goals for personal and professional development. Break them down from annual, to quarterly, monthly, weekly, daily! What do I want to accomplish today?
2. Do one thing at a time. Quality always suffers when you try to do too many things at once.
3. End the day by planning for tomorrow's projects whenever possible.
4. Protect yourself from constant interruptions. Block out time to complete tasks.
5. Work when you work best.
6. When all else fails, retreat to a hide out for time to work without interruptions.
7. When you know your energy level is dropping, take a break.
8. Throughout the day ask yourself, "What is the best use of my time right now?"

Caregiver Fatigue

Step back for a moment and complete the following brief fatigue syndrome survey. As you review your life over the past 12 months, answer the survey questions:

- 1) Do you generally feel fatigued and
- 2) Do you generally feel fatigued and lacking in energy?
- 3) Do you get irritable, impatient and angry with people around you at home and/or work?
- 4) Do you feel cynical and detached from the people in your care?
- 5) Do you suffer from more than your share of physical complaints such as headaches, stomach aches, back aches, and long-lasting colds?
- 6) Do you generally feel depressed or notice sudden fluctuations in your moods?
- 7) Do you feel busy yet have a sense that you don't accomplish much at all?
- 8) Do you have difficulty concentrating or remembering?
- 9) Do you think you have to be the one to help all those people experiencing grief?
- 10) Do you feel less of a sense of satisfaction about your helping efforts than you have in the past?
- 11) Do you feel that you just don't have anything more to give to people?

In general, if you answered yes to 2-4 of these questions, you may be in the early phases of caregiver fatigue syndrome.

If you answered yes to 5-7 of these questions, you are quickly moving in the direction of total fatigue.

If you answered yes to 8-10 of these questions, you are burned out!

Caregiver Perfectionism

Have you ever noticed the tendency among caregivers to be perfectionists? The checklist below will help you review whether you suffer from this malady and may encourage you to explore some alternative ways of accepting that all people are imperfect.

Check any of the following statements that apply to you.

- _____ I tend to lose patience with people if they aren't quick learners.
- _____ I have a reputation as being someone who is difficult to please.
- _____ I tend to want to do things exactly right every time I do something.
- _____ I get upset with myself when I don't do something well.
- _____ I tend to think I have only one opportunity to do things right, so I better not mess up.
- _____ I get frustrated when I play games and don't perform well.

If you checked most of these items, you may well suffer from perfectionism. At times it's hard to acknowledge this is an issue in your life, so you may want the opinion of friends and family who observe you.



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Caregiver Support Systems

The work of caregivers requires a natural outward focus on the needs of those we attempt to help. Such demands can leave us feeling emotionally and spiritually drained. An important aspect of self-care is to allow ourselves to have sounding boards for how this work impacts our lives. What do support systems provide for us? Ideally, supportive colleagues and friends provide some of the following:

- **Unconditional acceptance and support.** In other words, friendships and the need to be nurtured and understood.
- **Help with complicated situations.** Assistance in ideas that help us in our efforts to help the dying and the bereaved and their families.
- **Mentoring.** Encouragement to continue to develop new tools to assist us in our work. Models that inspire us and remind us of the importance and value of our work.
- **Challenge.** Encouragement to stretch ourselves beyond our current limits.
- **Referral.** Connection with additional resources for the people in our care. Good caregivers will recognize occasions when it is appropriate to refer those we work with to other sources of support and counsel.

Ask yourself, can I seek support systems when I need to? Who are the people in my life who make up my support system? List five people you could turn to right now for support and nurturing.

_____	_____
_____	_____
_____	_____

Are you involved in any relationships that are damaging to you? What would happen if you placed some boundaries on these relationships?

Review your current support system and make an honest assessment of how well it meets your needs. Identify areas where you could use some change.

Caregiver Time Management

Many caregivers never had the opportunity to learn essential time-management skills that result in working smart, not hard. You may find the following helpful:

- **Create specific goals for personal and professional development.** Separate your annual goals into monthly goals. Break up your weekly goals into daily goals. Ask yourself, “What do I want to accomplish this year, this month, this week, this day?” Planning each day can give you a road map to getting to your destination!
- **Do one thing at a time.** Caregivers are notorious for trying to do and be all things to all people and all projects all the time. Quality always suffers when you try to do too many things at once.
- **End the day by planning for tomorrow’s projects whenever possible.** That way, you’ll not only waste less time getting started the following morning, you’ll arrive at work feeling more in control of the day ahead.
- **Protect yourself from constant interruptions.** When you’re working on a task, nothing will sabotage you more than interruptions. Block out the necessary time to complete tasks.
- **Work when you work best.** We all have certain natural peak hours of performance. Pay attention to your inner clock. Are you a morning person or a night person? Does a brief nap recharge you?
- **Focus and reject.** This is a reminder to stay focused on the task at hand. Learn to “switch off” those things that prevent you from accomplishing desired tasks. Sometimes this means delaying returning calls and correspondence. If you always “stay available” you won’t have time to accomplish what you may really want and need to.
- **When all else fails, retreat to a hideout.** When working on project development, you may need to find a place where you can hole up with no interruptions. Tell only those who truly need to know where you are. You’ll be amazed at what you get done.
- **When you know your energy level is dropping, take a break.** After a ten-minute walk or a short nap, you may be able to accomplish much more than you could have done otherwise.
- **Delegate tasks whenever possible.** Watch out for “busy work” that might be done more efficiently by someone else.
- **Throughout the day ask yourself, “What’s the best use of my time right now?”** Focus on those tasks that need to be done first. This requires discipline but will pay many dividends.

Caregiver Self-Care

A SELF-CARE MANIFESTO FOR CAREGIVERS TO THE DYING AND THE BEREAVED

We who care for the bereaved and the dying have a wondrous opportunity: to help others embrace and grow through grief — and to lead fuller, more deeply-lived lives ourselves because of this important work.

But our work is draining — physically, emotionally and spiritually. We must first care for ourselves if we want to care for others. This manifesto is intended to empower you to practice good self-care.

- **I deserve to lead a joyful, whole life.**

No matter how much I love and value my work, my life is multi-faceted. My family, my friends, my other interests and my spirituality also deserve my time and attention. I deserve my own time and attention.

- **My work does not define me.**

I am a unique, worthy person outside my work life. While relationships can help me feel good about myself, they are not what is inside me. Sometimes I need to stop “doing” and instead focus on simply “being.”

- **I am not the only one who can help dying and bereaved people.**

When I feel indispensable, I tend to ignore my own needs. There are many talented caregivers in my community who also can help the dying and bereaved.

- **I must develop healthy eating, sleeping and exercise patterns.**

I am aware of the importance of these things for those I help, but I may neglect them myself. A well-balanced diet, adequate sleep and regular exercise allow me to be the best I can be.

- **If I've been over-involved in my caregiving for too long, I may have forgotten how to take care of myself.**

I may need to rediscover ways of caring for and nurturing myself. I may need to relearn how to explore my own feelings instead of focusing on everybody else's.

- **I must maintain boundaries in my helping relationships.**

I cannot avoid getting emotionally involved with dying and bereaved people, nor would I want to. Active empathy allows me to be a good companion to them. However, I must remember I am responsible *to* others, not *for* others.

- **I am not perfect and must not expect myself to be perfect.**

I often wish my helping efforts were always successful. But even when I offer compassionate, "on-target" help, the recipient of that help isn't always prepared to use it. And when I do make mistakes, I should see them as an integral part of learning and growth, not as measurements of my self-worth.

- **I must practice effective time-management skills.**

I must set practical goals for how I spend my time. I must also remember Pareto's principle: twenty perfect of what I do nets eighty percent of my results.

- **I must practice setting limits and alleviating stresses I can do something about.**

I must work to achieve a clear sense of expectations and set realistic deadlines. I should enjoy what I do accomplish in helping others but shouldn't berate myself for what is beyond me.

- **I must listen to my inner voice.**

As a caregiver to the dying and the bereaved, I will at times become grief overloaded. When my inner voice begins to whisper its fatigue, I must listen carefully and allow myself some grief down-time.

- **I should express the personal me in both my work and play.**

I shouldn't be afraid to demonstrate my unique talents and abilities. I must also make time each day to remind myself of what is important to me. If I only had three months to live, what would I do?

- **I am a spiritual being.**

I must spend alone time focusing on self-understanding and self-love. To be present to those I work with and to learn from those I companion, I must appreciate the beauty of life and living. I must renew my spirit.

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