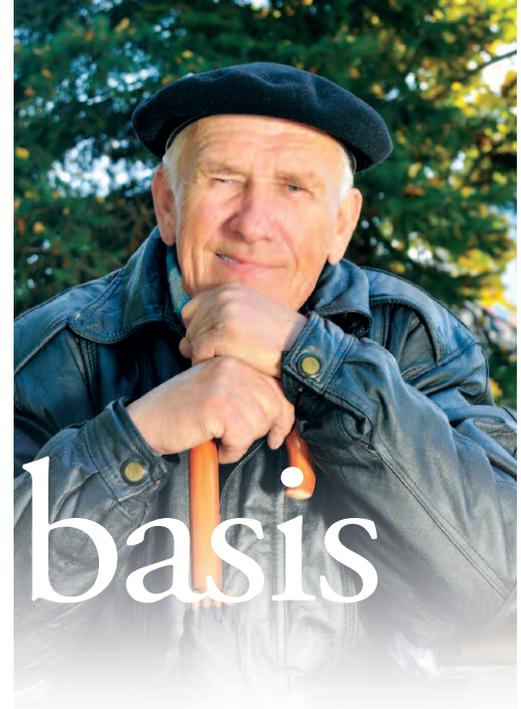


# Personalizing care: Preserving quality of life on an individual



By Carol Edwards, RN, GCM

*Saving for a “rainy day” is a good idea. Extended vacations and expensive hobbies may be fun, but are not always the reality in old age. In my books, preparations that ensure the maintenance of good health, dignity and control in later life are much more important.*

In the presence of debilitating healthcare issues or complex medical conditions, even a well-crafted “living will” and power of attorney cannot anticipate how events will unfold. So, when families are forced to face hard decisions, they are often ill prepared and have neither the time nor the expertise to understand the risks and implications of their choices. In these circumstances, one can only hope that those charged with arranging care will seek much-needed professional advice.

## *Changing circumstances*

Thankfully, these days there is increasing interest in planning early and considering ways to maintain “quality of life,” even in altered circumstances. Families and individuals are also aware of the benefits of recognizing personal preferences in the type of care a person wishes to have.

However, as part of my professional geriatric management practice I am often invited onto the scene in a crisis. Here are some tips I share with families to help them understand the ways in which they can personalize care to reflect their loved one’s needs:

- Maintain daily life at home for as long as possible.
- Keep familiar furniture, carpets and bedding.
- Discuss a smooth transition to a care facility.
- Plan for frequent positive family visits.

- Maintain a daily routine.
- Understand and preserve the “real person.”
- Personalize the caregivers and maintain consistent staff.
- Choose a physician for his or her skills and compatibility with your loved one’s needs (i.e., geriatrician vs. family doctor).
- Preserve familiar food.
- Encourage frequent exercise and physiotherapy.
- Keep pets close at hand.
- Minimize risks and prevent known side effects.
- Maintain humour and be “non-clinical.”
- Accept and understand the disease process as a “way of life.”
- Some of the simplest things produce the most pleasure. Each person is different, so find out what makes your loved one feel special.
- Think of positive outcomes whenever possible.

## *Understanding the “real” person*

During our lives we become who we are through our achievements and experiences. As we age it’s vital that others recognize and continue to value our achievements. Caregivers and family members should acknowledge and refer to a client’s/loved one’s achievements as often as possible to maintain their self-esteem. Sharing photos and memories of significant events is helpful.

## *Personalizing care through staff selection*

I find that using a homecare agency to help

“Youth deserves, middle age conserves and old age preserves.”

Martin H. Fischer

select staff for my clients saves money and takes the usual “random” selection out of the process. Members of my team act as advocates with the homecare agency and caregivers. This can also be done by an available family member.

The criteria that I use to select and pre-interview potential staff for my clients are:

- appropriate professional experience and references
- a positive attitude and calm disposition
- experience and fundamental understanding of the disease process
- respect and willingness to assist the client with autonomy
- pleasant tone and clarity of speech
- social compatibility with co-workers, clients and family
- caring and compassionate performance of tasks
- dedication, accountability and commitment to the family

### **Ongoing care**

Frequently, I am asked to manage and monitor caregivers because their client’s disease process is constantly changing. The recognition of subtle changes is imperative to prevent health hazards and unnecessary hospitalization. Often, part of the care plan is to transition to a long-term care home with familiar caregivers and family support. Transitioning with the same caregiver also helps take the “guilt” out of the nursing home transfer.

### **Arranging special activities**

While interest levels and abilities change based on the limitations of people and the stage of their disease, the most treasured activities are visits from family and friends. Based on my observations, the things that truly engage even the cognitively impaired are family meals together, outings, photos, “old movies,” drives in the country, hobbies, exercise and physiotherapy. I strive to maintain daily mobility through the assistance of regular physiotherapy services. Staying active affords people the benefit of remaining independent and in their own home.

### **Food basics**

Nutrition is extremely important in eldercare, so the preparation of familiar dishes and even the table setting is crucial to enjoyment. I consistently observe that when the elderly are eating

well, their health is better maintained. I recommend that close family members or a spouse actively assist in this process, even if it involves using prepared foods or a meal-delivery service. Companionship during meals is also key, as is assistance with shopping and meal planning.

### **Using humour**

I find that humour is often the best way to cope with challenging situations. It’s very hard for a family caregiver to consistently maintain a positive disposition in the presence of pressure from commitments to numerous tasks. With professional guidance it’s possible to juggle one’s many responsibilities and personal life, and it is much easier to reduce stress and maintain a sense of humour if help is close at hand.

### **Taking the right approach**

Alzheimer’s disease in particular is best accepted as a “way of life” rather than a disease. Accepting and understanding the progression and recognizing the “real person” during the process gives comfort to the caregiver as well as to the client. Many people wrongly believe that the impaired person is unaware of their surroundings as the disease progresses. Behavioural issues or distress are usually observed in or induced by unfamiliar surroundings, medications or the wrong approach. Confusion and upset can be avoided by maintaining familiar surroundings and consistent staff who understand the person and conduct unhurried care.

### **Best possible solutions**

As caregivers and family members, we strive to provide and enrich “quality of life” and “peace of mind” by understanding both the person and family values. Orchestrating the best outcomes given the circumstances is most desirable.

While many of us have not considered paying for care planning or management, arranging the best care possible is usually a priority when the time comes. After all, is this not the “rainy day” that we’ve been expecting (and saving for) all our lives? ●



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## **Planning for a seamless approach**

Here are some tips to assist families with seamless planning:

- Assess and understand the disease(s) and potential risks and outcomes.
- Formulate and cost an action plan. Often it’s cheaper to anticipate and take steps ahead of a crisis.
- Act as your loved one’s advocate within the public system.
- Involve the appropriate public professionals such as the Community Care Access Centre and its allied support such as physiotherapists, occupational therapists and future long-term care placement.
- Seek financial guidance from banks, accountants and trust officers.
- Seek legal advice around the use of power of attorney and other legal instruments.
- Monitor your loved one’s progress and keep good records.