

Respite: A Break from Caregiving

Throughout our lives, we work, spend time alone or with friends and take time for leisure. Most of us are not used to spending 24 hours a day with another person. When someone is faced with Alzheimer's disease and becomes a caregiver, he or she may have to juggle this new role along with many other responsibilities. Some caregivers work and have other responsibilities besides providing care. Respite care can give the caregiver the time and assistance needed to meet personal needs as well as other responsibilities.

What is respite care?

Respite refers to a short time of rest or relief. It allows the caregiver a break from day-to-day duties while the person with dementia receives care from qualified individuals. There are many different ways respite care can be provided. Respite care can be provided in a home, community organization or residential facility. It can be for part of the day, evening or overnight on a regular basis, or occasionally.

Respite care is given by paid staff, volunteers, family or friends. It can be very beneficial to the health and well-being of the person providing care as well as the person with dementia.

Why use respite care services?

Respite care can provide the caregiver with:

- A chance to spend time with friends and family, or just to relax.
- Comfort or peace of mind knowing that the person with dementia is safe while he or she is away.
- Time to get things done, such as errands, shopping or going to the doctor.
- Time to care for one's self, such as getting a haircut, exercising or going fishing.

The person with Alzheimer's disease is also faced with many changes and challenges. Spending many hours together or living with another person may be a new experience. He too many need time away. In addition, not being able to do things as independently can create many frustrations.

Respite care services can provide the individual with dementia with:

- An opportunity for one-on-one attention and a fresh approach from a respite care aide. (This may be difficult for the caregiver to provide when involved in daily chores and responsibilities.)
- A chance to get out of the house, participate in enjoyable activities and socialize with others.
- An opportunity to be around others who are having similar challenges.
- Time away in a safe environment with activities structured to meet his or her abilities and needs.

There is always apprehension when trying something new. It can be difficult to accept help from others. Many people try to "do it all" on their own, or believe no one can do it as well. This can quickly become exhausting and overwhelming. It is important to recognize the short-term and long-term benefits of respite care services for both the caregiver and the person with dementia.

Some concerns about using respite care services may be:

- Cost. You may be concerned about how to pay for services or about depleting your savings.
- Reliability. You may be concerned about the dependability of the aide or service.
- Guilt. You may believe that you should be able to do it all.
- Anxiety. You may be concerned about meeting someone new or having someone come into your home.

Different types of services that provide respite care are:

- In-home respite care.
- Adult day centers.
- Residential respite care.
- Informal respite care.
- Respite care for emergencies.

Selecting respite care services

While selecting respite care services in your home, you may want to ask a home health agency or individual some of the following questions:

- Why are you interested in this job?
- What is your training?
- What are your past/current home care experiences?
- Have you ever worked with someone with dementia?
- How would you handle ... ? (Give examples of behaviors or situations)
- Do you have any special skills, e.g., Activities?

When/how often are you available? Do you have a back-up if you are unable to come?

- Are you bonded?
- Who can I talk with your agency if I have a concern?
- Tell me about yourself. Interests? Hobbies?
- Why did you leave your last job?
- Do you have references?

When selecting an adult day care service or short term stay in a facility, you might want to ask some of the following questions:

- What are the hours? Fee? Services?

- Is transportation available? Can you suggest transportation options?
- What types of programs and activities do you offer?
- Are people with dementia separated from other participants or included in general activities?
- How many participants is each staff member responsible for?
- Have they been trained in dementia issues?
- Do they help with personal care?
- How do they handle ... ? (e.g., wandering)
- Is there a nurse on staff? Social worker?

Other professionals?

- Are there individual plans of care? How are different functioning levels addressed?
- Do they serve meals/snacks?
- How are emergencies handled?
- How do you ensure safety?
- What are the reasons for discharge?
- Are there other services offered? (e.g .support groups, training & education, case management)

What is the philosophy of care? What are your beliefs about caring for someone with Alzheimer's?

- How do they view Alzheimer's?
- How many residents is each staff member responsible for during the evening? at night?
- What types of programs are offered? Are they designed for people with dementia?
- Is there a full day of activities? How many hours a day?
- How will you meet the special needs of persons with dementia?

Can you handle ... ? (give examples of behaviors or situations)

- Is there an indoor place that allows people to walk/move around freely?
- What is your view on physical restraints?
- What is their view/policy on medication?
- How are they monitored?
- What are the qualifications of the staff?
- What training do they receive? Is it ongoing?
- What is a typical day (evening, weekend) like for a resident?

For the caregiver: What to do with your time

Now that you have time for yourself, you may want to:

- Get things done. Go grocery shopping, to the bank, run errands, take care of all those little things you have put off.
- Care for yourself. Visit friends, see a movie or go to a museum. Relax. rest and

refresh yourself.

- Be an individual. You are more than a caregiver. You will not be in this role forever, and it is important to maintain your past and current friendships and interests.

Remember, your health and well-being are important. The healthier you are, the better able you are to deal with the demands, and responsibilities of caring for a person with dementia.

Courtesy Alzheimer's Association. Hawaii Chapter