

KANSAS DEPARTMENT ON AGING

How to Select a Special Care Unit



A Consumers Guide to Special Care Units for Persons with Dementia

Introduction

Family members are faced with many challenging decisions when considering placing their loved one with special needs in an adult care facility. There is no perfectly “right” time for placing the person with Alzheimer’s disease in a facility. The timing depends on the needs of the individual and the ability of the caregiver to meet those needs. Remember also that it takes time for both the family and your loved one to adjust to the new surroundings. Allow several weeks for this adjustment to occur.

This guide is intended to assist families in the selection of a dementia special care unit (SCU) within an adult care facility. The information in this guide can be used in discussions with the administrator and staff of a facility about the services and programs offered by their special care unit. Although the focus of this booklet is on special care units within adult care facilities, many of the same guidelines may be used in choosing other adult care settings.

Special care units within nursing facilities are not the only residential care options available for individuals with dementia. There are also alternative settings which focus on a smaller, less institutional models of care for those with Alzheimer’s disease and similar disorders. Explore all residential care options available in your area.

Photograph on cover: **Brand X Pictures**

The Kansas Department on Aging (KDOA) does not discriminate on the basis of race, color, national origin, sex, age or disability. If you believe you have been discriminated against by either KDOA or a KDOA funded program, please contact KDOA to receive additional information on filing a complaint: 1-800-432-3535 (voice); 1-800-766-3777(TTY).

Table of Contents

CONTENT	PAGE
Alzheimer’s Disease and Related Dementia	2
Evaluating Special Care Units	3
Management of the Special Care Unit	5
Special Care Unit Environment	7
Daily Resident Care	8
Therapeutic Programming	9
Special Care Unit Cost	10
Resources	11

**A list of Kansas Special Care Units and additional copies
of this document can be obtained by contacting:**

Kansas Department on Aging

503 S. Kansas Avenue
Topeka, KS 66603-4304
800-432-3535
785-296-4986
www.agingkansas.org

Updated October 2008

Alzheimer's Disease and Related Dementia

Dementia is a general term for several diseases that cause changes in an individual's orientation, ability to remember, reasoning and judgment. Ability to learn, personality, language skills and a person's perception can also be affected. The losses caused by dementia interfere with a person's ability to function normally in personal, social and occupational activities.

Alzheimer's disease accounts for over half of all dementias. It is an irreversible, progressive brain disorder that occurs gradually and results in memory loss, behavior and personality changes and a decline in thinking abilities. These losses are a result of the death of brain cells and the breakdown of the connections between them. The course of the disease and the rate of decline vary from person to person. Though the disease can last for up to 20 years, on average individuals live for 8-10 years after they are diagnosed. Alzheimer's disease is the 4th leading cause of death among adults after heart disease, cancer, and stroke.

The National Institute on Aging estimates that about 4.5 million Americans suffer with the disease. The risk of Alzheimer's disease increases dramatically with age. It does not discriminate on the basis of race, education, economic status, culture or gender.

It is essential that individuals who exhibit symptoms of confusion, loss of memory, disorientation and behavior changes be thoroughly evaluated. The examination should include a medical history, mental status evaluation, physical and neurological examination, laboratory tests and psychiatric evaluation.

The individual with Alzheimer's disease progresses from an independent adult to an individual who becomes totally dependent upon others. There are services in the community that can assist in caring for the person at home. A description of services available in your community is listed in *Explore Your Options: A Kansas Guide to Information and In-Home Services*. You can receive a copy by contacting your local Area Agency on Aging or by calling the Kansas Department on Aging at 800-432-3535.

As the disease progresses into the later stages, the individual will require 24-hour care. Due to the excessive physical and emotional demands placed upon the caregiver, it can be very difficult to provide this constant level of care in the home. Admission to an adult care facility can often relieve caregivers by providing 24-hour care.

There are resources available that can help you further understand this disease. The booklet, "A Guide for Alzheimer's Disease and Related Disorders" is available from the Kansas Department on Aging at 800-432-3535 or online at www.agingkansas.org/publications.

Your Alzheimer's Association chapter office may also have publications and other information that can help you care for your loved one. See pages 11 & 12 for contact information.

Evaluating Special Care Units

Locating a facility, either a regular nursing facility or a Special Care Unit (SCU) requires time and careful planning. It is beneficial to start the process early so you can avoid having to make a decision in a time of crisis. Kansas law requires a Client Assessment, Referral and Evaluation (CARE) be completed for all persons prior to entering any Kansas adult care home. You may contact your local Area Agency on Aging office to schedule an assessment.

Families are encouraged to evaluate several facilities before making a decision. Visit the facilities you are interested in at various times of the day. Arrange to visit and eat with the residents during a mealtime. Once you have chosen a facility, begin the admission process. This process may include being placed on an admission waiting list, and reviewing financial costs and resources for payment.

Ask questions of the administrator and staff. Remember, they want to provide you with information that will assist you to make an informed decision. Information about the quality of care in nursing homes in your area is available on the Medicare website www.medicare.gov or by calling 1-800-MEDICARE. This quality information is just one tool you can use during your decision-making process.

Policies

Resident care policies are developed to provide specific guidelines for the staff regarding the care of residents.

Admission, Transfer and Discharge Policy

1. What are the criteria for admission to the SCU?

Facilities must obtain a physician's order for admission of a person to a SCU. It is appropriate for the facility to have an assessment process which identifies persons who could benefit from the SCU program. Request a written copy of the criteria.

2. What are the criteria for transfer or discharge from the SCU and general nursing facility?

Federal regulations protect the rights of the person with dementia to remain in the nursing facility and limit the conditions under which the facility may transfer or discharge the resident. The following conditions must be met for transfer or discharge of a nursing home resident:

- Another level of care is needed based on a physician recommendation. Such as, the resident's health has improved and services are no longer needed or a resident is demonstrating care needs that would best be served at a level of care other than the SCU.
- The resident, after reasonable notice, has failed to pay agreed upon nursing home charges. (Note: Use of Medicaid funding cannot be considered as non-payment).

Evaluating Special Care Units

- The resident's presence threatened either the health or safety of other residents **and** the resident or legally responsible representative rejects recommendations for hospitalizations and treatment. It is common for a person with dementia to become combative at some time during the illness. If this happens, a thorough medical and psychiatric evaluation should occur. This would be considered therapeutic leave and would not be justification for eviction.
- The facility ceases to operate.

3. How will the family and/or guardian be involved in planning the resident's care?

Each resident must have a plan of care based on the orders of the attending physician. The plan also includes an assessment of the person's needs. It also identifies how the staff (nursing, dietary, social service and other staff) will handle each of the problem areas. Identify how the facility specifically involves the family in this process. The family/guardian should be involved in developing the resident's care plan. They are a valuable resource to help staff identify the resident's routine behaviors, likes and dislikes.

Family/Guardian Notification Policy

1. What is the policy for notifying the family/guardian when the resident has episodes of difficult behavior or an incident which could be potentially harmful to self or to others?

Families can often assist staff in understanding the reasons for the behavior. When the reasons for specific behaviors are understood, they can often be controlled or eliminated.

2. How is the family/guardian notified when there is a significant change in the physical, mental or social status of the resident?

There should be an established policy of notification. Some facilities will notify the family/guardian whenever a significant event occurs; others will notify only in those instances when a physician is notified of a change. The family/guardian should let the facility know under what circumstances notification is desired.

Visiting Hours Policy

1. What are the preferred visiting hours?

Residents have the right to have visitors at anytime. However, because of the needs of some residents, the facility may discourage visiting during certain times of the day and night. Family and friends should try to visit frequently and on a schedule. Staff can then help your loved one remember when you are coming to visit.

2. Are families allowed and encouraged to participate in activities while visiting?

Family members should be allowed to actively participate in special activities as well as the SCU's daily routine if they desire.

Management of the Special Care Unit

The management of the unit should ensure that each resident is provided with constant supervision by well-trained staff. Adequate medical care, social interaction, and appropriate programming should be provided to each resident.

1. Who is the person in charge of the SCU?

Ask to meet with this person. Some SCU's employ specific individuals to be a director of the unit while others add this responsibility to existing positions, such as nursing or social service positions.

2. How many hours does the person in charge of the unit work directly with the residents?

Discuss what an average work day and work week is for that person and the best time for family to contact them.

3. What type of decisions can the SCU director make and what authority does this person have regarding unit programming and staff?

Identify what job duties this person has and how those duties affect the unit programming, resident care, unit staff, unit marketing, resident families and the community.

4. How many hours of training does the staff receive before and while they are working on the SCU. What training program is utilized?

You will be able to see the result of the training through the resident care and management on the unit. Training topics can include normal aging, stages of dementia, behavior management techniques, personal care,

meaningful program activities, family/caregiver issues, coping strategies for the professional caregiver, spirituality, and communication with persons with dementia. Inquire if other staff such as the housekeepers, laundry and kitchen staff who would interact with the residents on the unit also receive dementia specific training. Ask to review the training curriculum.

5. What methods do staff use to manage difficult resident behavior?

Ask the staff to describe current methods used in dealing with difficult behaviors, including the behaviors the person with dementia displays. Difficult behaviors may include day and night wandering, incontinence, agitation, catastrophic reactions, verbal aggression such as screaming, and physical aggression.

6. When are physical restraints used and for what purposes?

Physical restraints should not be used to manage difficult behavior. However, there are instances when the use of a physical restraint is may be appropriate to prevent further injury due to a resident's medical condition. For example, a resident has a healing fractured hip and has a "no weight bearing" physician order. Since the person with dementia does not understand they are not to walk, a restraint in this situation may be appropriate. However, there must be procedures in place for observation and monitoring when the restraint is in use. Only a physician can order a restraint. The resident's family or guardian must also be consulted concerning the use of a physical restraint and agree to the use of the restraint.

Management of the Special Care Unit

7. How are psychotropic drugs used on the SCU?

Psychotropic medications may be ordered by the physician to treat specific symptoms of dementia. Ask under what circumstances would the staff recommend the use of a psychotropic drug. When these drugs are used, the resident should be assessed frequently to determine possible side effects and when the dosage can be reduced or discontinued.

8. Are medications to promote sleep routinely given?

Difficulty in falling asleep or only sleeping for short periods of time is normal for a person with dementia. There are some medications that can be helpful for short term use. Sleep aids should only be used for a short time while other non-drug treatments are tried. The facility should also have warm food and drink available for the person who is up at night.

9. How does staff identify when the person with dementia has unexpressed pain?

People with dementia usually lose the ability to express bodily discomfort or pain. Staff will need to watch for signs of unexpressed pain. Appropriate pain medication should be given to the person as ordered by the physician.



Photograph: **Gardener Hands**

Photographer: Lesleigh Bahnmaier, Lenexa, Kansas

Subject: Earl Bahnmaier

*Photograph courtesy of the Landon Center on Aging,
Images of Aging Photo Contest*

Special Care Unit Environment

Special Care Units have many different designs. A number of Kansas facilities have developed SCU's from existing units, while others have built new units. It is important to remember that while the architectural design may be important, the environmental design is more important. The environmental design must allow residents with dementia to function in the least restrictive manner possible at the highest level of independence possible. Remember, persons with dementia are directly and indirectly affected by their environment.

1. How is the SCU separated from the rest of the facility?

The unit may be a separate wing or section of a building.

2. What precautions are used to ensure the safety of residents?

SCU's usually have locked door(s) going into the units which are closed to discourage wandering and decrease stimulation. Ask what precautions are used to ensure fire safety for residents in a locked unit.

3. Does the environment of the unit reduce stimulation while creating a homelike atmosphere?

Experts in the care of persons with dementia recommend that bright lights and glare be avoided. The decorations should reflect a comfortable, warm environment. The use of contrasting colors may aid vision. Comfortable furniture, such as recliners and chairs that are easy to get in and out of encourages residents to relax and rest at intervals. Plants should be nontoxic.

4. What efforts have been taken to reduce the level of noise?

Too much noise can cause fear, confusion and frustration. Sounds that do not contribute to a pleasant environment should be reduced or eliminated.

5. How are resident rooms identified?

Name plates on the doors should be in large print with the resident's complete name. Many facilities decorate the door with a picture of the resident or an item which will assist residents to find their own room.

6. Are resident rooms decorated with personal belongings?

A favorite chair, blanket, chests of drawers, pictures and other decorative items will assist a resident to identify an area as their own.

7. Is there an outdoor area available to the residents?

There should be direct access from the unit to the outdoor area. Ensure that the plants and pesticides are nontoxic.

Provisions for shade and comfortable seating will encourage residents and their families to use the area. Fencing and controlled exits must be used to prevent the resident from wandering from the facility.

A walking path that allows residents to move about freely outside can be beneficial.

Daily Resident Care

There is a tendency for everyone to want to do as much as possible for a person with dementia. The assistance given this person directly affects their level of independence. It is important and beneficial for caregivers to allow and enable the person with dementia to be as independent as possible in his or her current stage of the disease.

1. How are activities of daily living managed?

Each resident should be allowed and encouraged to perform the activities of daily living independently or with the least assistance possible based on their capabilities. The staff should not perform tasks for the resident which can be accomplished independently. Many individuals with dementia can dress themselves if staff allows adequate time and provide verbal prompting.

2. What is the routine for activities of daily living on the SCU?

Each day should have a schedule. Even though there is a schedule, determine how flexible the staff is in adapting to the needs of each resident as things change from day to day.

3. How are meal times managed?

Mealtimes should be designed to encourage the involvement and socialization of residents. Food should be served in a manner which encourages independence in eating. Many residents in the middle stage of dementia can remain independent in eating if finger foods are served or adaptive utensils are provided. Also, identify how the nursing and dietary staff ensures that each resident is adequately nourished.

4. How often is the health of each resident monitored by a licensed nurse?

Monitoring the health of an individual with dementia can be difficult. The ability of the person with dementia to express a physical condition decreases as the disease progresses. Therefore, it is often impossible for the person with dementia to identify and communicate a health concern to another person. A licensed nurse with knowledge of dementia should perform regular health assessments of residents and be available when, and if, a change in the resident's clinical condition occurs.

5. What does the staff do to make sure the resident receives adequate fluid intake?

Persons with dementia do not usually ask for fluids and often cannot remember to drink or how to turn the faucet on. It is very important to have water, juices and other fluids offered at routine intervals.

Therapeutic Programming

There are two types of therapeutic activity levels. The organization level includes such activities as art, music, drama and exercise. The informal level is the continuous flow of activities occurring throughout the day, including the evening. Positive changes in resident behavior can occur through the use of specific types of activities conducted in a therapeutic manner. Such changes include improved eating and sleeping patterns, less wandering, less restlessness and less agitation.

1. What is the daily therapeutic activity schedule for the SCU?

A daily schedule of these activities should be provided which includes periods of mental activities alternated with physical exercise. Activities should be planned for every day and include evenings and weekends.

2. What types of activities are used?

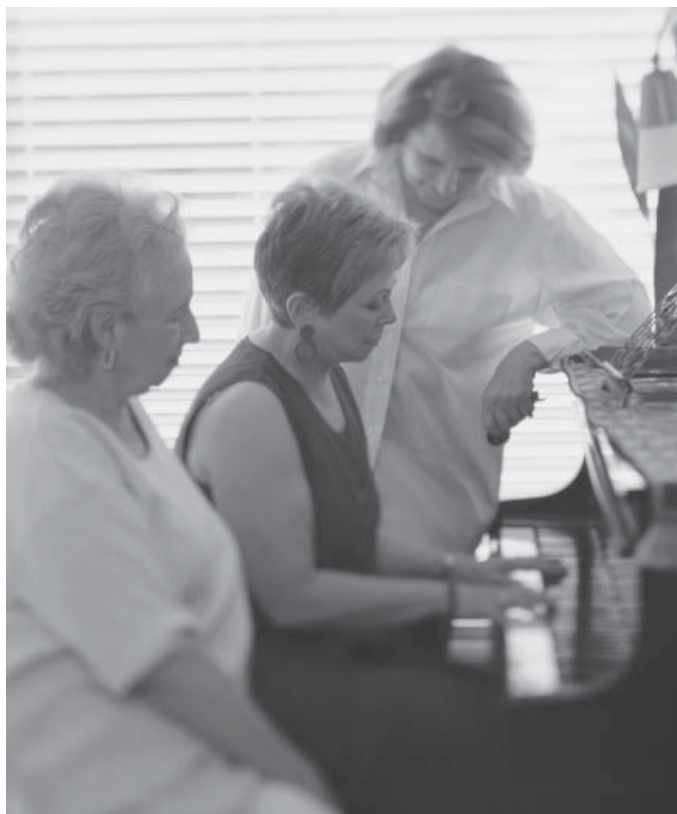
Therapeutic activities need to be meaningful, enjoyable, purposeful and success oriented. Activities that involve sensory experiences, music, exercise and physical movement are beneficial.

3. Who develops, organizes and conducts the activity programming for the SCU?

Discuss the background and knowledge this individual has in working with residents with dementia. Identify the individuals who perform the activities when this person is not on the unit. All unit staff should be trained in the application of therapeutic activities.

4. What types of physical activities and exercises are used on the unit?

Regular physical activity is very beneficial for residents with dementia. Walking, exercise/movement programs and stretching are a few examples. When opportunities for adequate physical activity are provided, incidents of difficult behavior are reduced.



Special Care Unit Cost

The costs of SCU's vary widely in Kansas. The following costs should be discussed with the admission personnel.

1. What is the daily rate charge of the SCU and what specific services are included in the daily rate?

The facility should provide written information on all rates, charges, the resident's obligation regarding payment and refund information.

2. What specific services are not included in the daily rate?

There may be additional charges for nursing supplies, laundry, toiletry items, activities, transportation, telephone, beautician/barber.

3. What is the facility's grievance procedure for addressing disagreements with any charges?

Inquire if the facility has a procedure in place to address any billing disputes.

4. Does the facility participate in the Medicaid program?

The administrator or the social worker can provide information about this program that can assist residents in meeting the costs of nursing facility care.

5. Can the administrator or social worker provide you with information concerning the Spousal Impoverishment Law also called Division of Assets?

Married couples should be familiar with this law. If needed, a couple is able to preserve a portion of the couple's income and/or assets for the spouse who will remain in the family home. This law saves the spouse at home from impoverishment while ensuring funding for the spouse in the nursing facility. Information on the Division of Assets can be obtained by contacting your local Area Agency on Aging's law project, Kansas Legal Services or the Kansas Department on Aging. A booklet "Q&A on Spousal Impoverishment," is available from the Kansas Department on Aging at 800-432-3535. It's also available online at www.agingkansas.org/publications.

Resources

Kansas Department on Aging

503 S. Kansas Ave.
Topeka, KS 66603-3404
785-296-4986 or 800-432-3535

Kansas Alzheimer's Disease Information

Alzheimer's Association
Heart of America Chapter
3846 W. 75th Street
Prairie Village, KS 66208
913-831-3888 or 800-272-3900

Alzheimer's Association
Heart of America Chapter
Northeast Kansas Regional Office
4125 SW Gage Center Dr, Ste LL 15
Topeka, KS 66604
785-271-1844 or 800-272-3900

Alzheimer's Association
Central and Western Kansas Office
347 S. Laura
Wichita, KS 67211-1518
316-267-7300 or 800-272-3900

Kansas Nursing Home Information

Kansas Advocates for Better Care
913 Tennessee, #2
Lawrence, KS 66044
800-524-1782 or 785-842-3088
www.kabc.org

Kansas Association of Homes and
Services for the Aging
217 SE 8th
Topeka, KS 66603
785-233-7443
www.kahsa.org

Kansas Health Care Association
117 SW 6th, Ste 200
Topeka, KS 66603
785-267-6003
www.khca.org

Legal Advice and Referral Service

Kansas Elder Law Hotline
888-353-5337

Resources

National Alzheimer's Disease Information

Alzheimer's Association
National Office
225 N. Michigan Ave., Fl 17
Chicago, IL 60601
800-272-3900 24/7 helpline
www.alz.org

National Institute on Aging
Alzheimer's Disease Education and
Referral Center (ADEAR)
P.O. Box 8250
Silver Spring, MD 20907-8250
800-438-4380
www.alzheimers.org/adear

Reporting Concerns of Residents Health Care and Safety

Kansas Department on Aging
Licensure, Certification & Evaluation
503 S. Kansas
Topeka, Kansas 66603
800-842-0078

Kansas Long Term Care Ombudsman
900 SW Jackson, Suite 1041
Topeka, KS 66612-1616
785-296-3017 or 877-662-8362

Support Groups

There are more than 80 Caregiver Support Groups in Kansas. The groups can offer information, material resources and support. Contact the nearest chapter of the Alzheimer's Association to locate a support group in your area.



DEPARTMENT ON AGING

New England Building

503 S. Kansas Avenue

Topeka, KS 66603

1-800-432-3535

www.agingkansas.org