

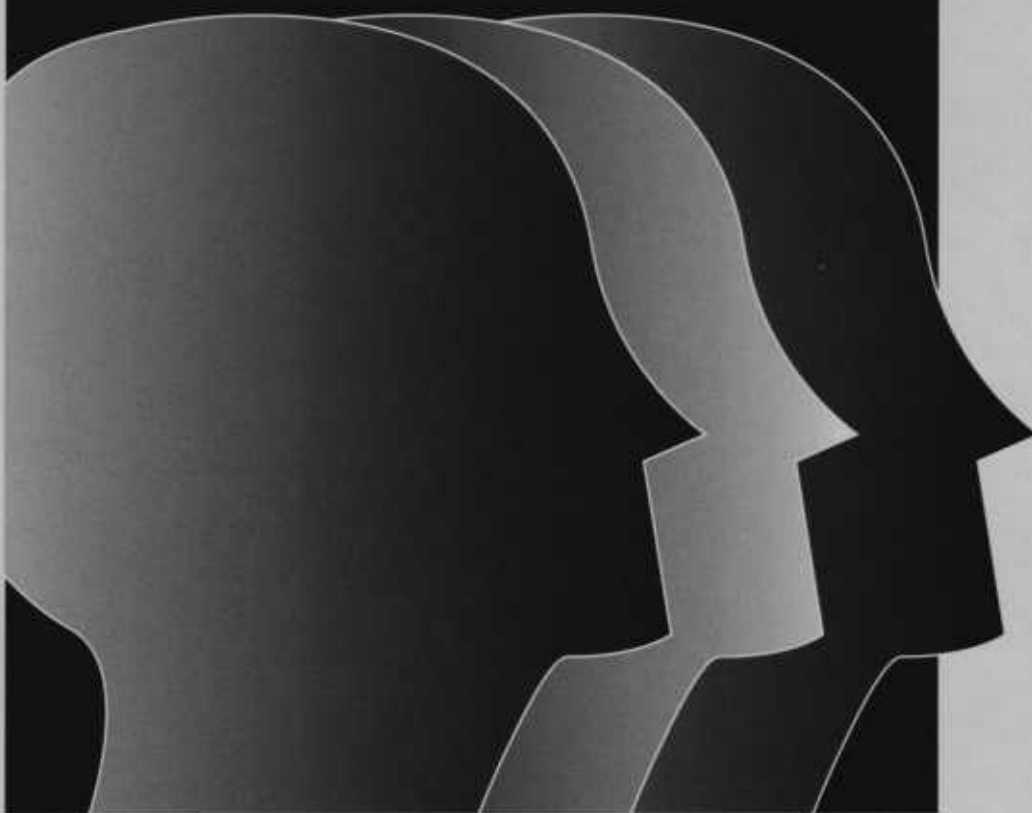
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AN OREGON GUIDE TO

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SPECIAL CARE UNITS
FOR PERSONS WITH

DEMENTIA



OREGON STATE UNIVERSITY EXTENSION SERVICE

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Contents

	<i>Page</i>
Special Care Units for Persons with Dementia	1
State Regulations of SCUs	2
The Needs of Persons with Dementia	2
Special Care Units in Oregon—What to Look For	3
An Oregon Survey 1992.....	3
Levels of Care	3
Length of Operation	4
Special Care Unit Size	4
Design Features	5
Staff and Nursing Staff/Resident Ratios	6
Staff Characteristics and Training.....	7
Philosophy of Care and Goals	8
Resident Services	9
<i>Resident Care Policies</i>	9
<i>Admission</i>	9
<i>Transfer and Discharge</i>	10
Family Involvement	10
Activities of Daily Living	12
Therapeutic Programs and Care Provision	13
<i>Activities Programs</i>	13
<i>Other Therapeutic Services</i>	13
Cost of the Unit Care.....	14
Summary	15
Additional Resources	16
For Further Reading	inside back cover

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Special Care Units for Persons with Dementia

S.A. Baggett and C. Pratt

As the needs of the older person with dementia increase, families often find that a long-term care facility can provide the care and supervision their relative needs. Some nursing homes and other residential facilities provide special activities and physical environments for residents with dementia. In Oregon, as across the country, these facilities are called special care units, designated units, or dedicated units. This publication will use the term special care units (SCUs).

In order to focus specifically on the needs of persons with dementia, SCUs physically separate persons with dementia from the other residents. To create this physical separation, facilities may simply close the doors in a wing of a building, or construct a free-standing building devoted to the care of residents with Alzheimer's disease and other dementias. Physical separation of residents with dementia is the essential characteristic of an SCU, although many SCUs also have special programming and design.

SCUs are only one option for caring for persons with Alzheimer's disease or other dementias. Many nursing homes and residential facilities provide high-quality care for residents with dementia in an environment where residents with different needs live together.

This publication will help you determine which facility and which program of care is right for your family member, friend, or client. In Oregon, SCUs are found not only in nursing homes, but in residential care facilities, foster homes, and assisted living facilities. This publication provides information about SCUs with special emphasis on Oregon's facilities and Oregon state regulations regarding care in these specialized units.

By knowing what SCUs in Oregon provide and how they compare to other facilities, you can make an informed decision about which type of care is best for the needs of a particular individual with dementia. Included throughout this publication are specific questions to help you assess the type and quality of programs available to a dementia patient. These questions are designed to help you investigate SCUs; however, many also are useful in exploring the care provided to dementia patients by any long-term care facility.

Sharon A. Baggett, assistant professor, Department of Human Development and Family Sciences; and Clara Pratt, professor, Department of Human Development and Family Sciences; and director of the gerontology program, Oregon State University.

State Regulations of SCUs

In 1991 the State of Oregon passed Senate Bill 801, which requires a special license or registration endorsement for facilities with Special Care Units for patients with dementia. By June 1, 1993, standards of care must meet a minimum level of compliance with all of the areas described in this publication. You can ask the administrator to show you the SCU's endorsement.

The Needs of Persons with Dementia

Although millions of older persons develop dementia, this is not a normal part of the aging process. Dementia is the result of the destruction of brain cells, but it is not known what causes this destruction in all cases, nor is there a cure.

About two-thirds of dementia residents in nursing homes have Alzheimer's disease. One-third suffer from dementia due to other diseases such as stroke, Parkinson's disease, chronic alcoholism, Huntington's disease, and other causes of brain impairment. Special care units normally require a diagnosis of dementia for admission. Most have additional criteria as well; these are discussed later in this publication.

The needs of people with dementia vary greatly, and change with time. Individuals with dementia progress from independence, to needing reminders throughout the day, to needing assistance with some activities of daily life (such as bathing, dressing, and grooming), to total dependence in the later stages of the disease. As dementia progresses, patients become less able to concentrate. Wandering also is common. They may be uncooperative, irritable, and combative. They need fewer demands on their performance.

Admission to a long-term care facility—with or without a special care unit—may be beneficial for individuals with dementia whose needs exceed what families and community services can offer. An SCU designed to supervise, allow safe wandering, and provide activities suited to short attention may benefit the resident with dementia. Specially trained staff can provide a setting in which a resident's changing needs can be carefully monitored and addressed.

Special Care Units in Oregon— What to Look For

An Oregon Survey, 1992

A survey completed in 1992 by Oregon State University's Program on Gerontology found 36 special care units in Oregon. Thus, approximately 12 percent of Oregon's 296 long-term care facilities had SCUs in late 1991 and early 1992. All specific numbers presented in this publication are based on findings from this survey.

Levels of Care

In Oregon, special care units are found in three kinds of long-term care facilities: nursing homes, residential care facilities, and assisted living facilities. In 1992, about 60 percent of Oregon's SCUs were located in nursing homes, with the remaining 40 percent largely in residential care facilities. Most special care units in Oregon are found in urban and suburban areas and small cities. Very few are located in communities with fewer than 20,000 residents.

Nursing homes provide the most complete nursing, medical, rehabilitation, and personal care services available outside a hospital setting. Care is given to chronically ill and/or convalescing persons by licensed professional staff. Nursing homes offer two levels of assistance: skilled care, for residents who need intensive medical intervention or rehabilitation; and intermediate care, for residents whose medical and physical needs require less intensive nursing supervision. In 1992, 21 (11 percent) of Oregon's 183 nursing homes had SCUs.

Residential care facilities (RCFs) provide daily assistance with personal care (such as bathing and dressing), monitoring of medications, meals, laundry, and housekeeping. Most residents share rooms, although some RCFs have limited private rooms. Some nursing homes have residential care sections. In 1992, nine (9 percent) of Oregon's 99 RCFs had SCUs.

Assisted living facilities (ALFs) provide daily assistance with personal care, monitoring of medications, meals, laundry, and housekeeping. These facilities differ from RCFs in that residents typically have private apartment units. In 1992, three (21 percent) of Oregon's 14 ALFs had SCUs.

Keep in mind the level of care available when looking for a special care unit. This is important because some facilities, such as those offering

residential care or assisted living, may limit the degree or kind of care they provide. Cost also varies by level of care. Consider both the current and the future needs of the person with dementia.

Q QUESTIONS TO ASK

- In what level of care (nursing, RCF, ALF) is the special care unit found?*
- Does this level of care match the current needs of the person with dementia?*
- What will happen as the person's needs change? Are alternative levels or type of care available?*

Length of Operation

Special care units are new. In 1992, 56 percent of the 36 special care units in Oregon had been in operation less than 18 months. About one-third had been in operation less than 6 months. When viewing facilities and their programs, keep in mind that many are new and still may be refining their approach to care.

Q QUESTIONS TO ASK

- How long has the unit has been in operation and what changes have occurred since the SCU opened? Are other changes planned?*

Special Care Unit Size

In 1992, the average special care unit in Oregon had about 30 beds, comprising approximately 43 percent of the total number of beds in the facility. The small size, which enables staff to provide more one-on-one care, is a hallmark of dementia care. If a unit is large, observe and ask how they give individual care and attention.

Q QUESTIONS TO ASK

- How many beds are in the SCU?*
- How do staff provide individualized care? For example, does a large unit create smaller "subunits" for more individualized care?*

Design Features

Most SCUs have a physical environment designed to enhance the care of residents with dementia. The most common design modifications include alarming or securing of exits; securing patio or garden areas; and using large letters, numbers, or pictures to help residents find their way in the facility. It may be helpful to use patients' personal objects to help them identify an area as their own. Current thinking about the care of persons with dementia also supports avoidance of bright lights and bright colors and encourages simple decorations. Comfortable furniture such as recliners and rockers encourage residents to relax and rest frequently. Plants should be non-toxic.

Some SCUs use "visual barriers" such as stop signs by exits to discourage wandering. Entrances to SCU units usually are closed to discourage wandering and to decrease stimulation. A secured outdoor area provides space for exercise, allows for walking safely, and can be used for activities such as gardening.

Noise reduction reduces stimulation and may benefit persons with dementia. Many SCUs avoid the use of the public address system, and limit or prohibit television and radios in the common spaces.

New state regulations also require that SCUs have their own dining room and/or activity area, and many SCUs have adapted their units to provide several small gathering spaces rather than one large sitting room. Almost half of the SCUs responding to the 1992 survey had modified their nursing station in order to limit resident access.

In 1992, almost 60 percent of Oregon's special care units reported that their unit was created by converting an existing wing or section. Another 15 percent reported new construction of a free-standing building specifically for this purpose.

- How is the SCU separated from the rest of the facility?*
- If the unit is locked, what precautions are used to ensure the safety of residents in an emergency?*
- Is the unit's environment homelike, and does it reduce stimulation?*
- What efforts have been made to reduce noise?*
- How are residents' rooms identified? Does the facility use a picture or other familiar object on the door to help the residents find their own rooms?*
- Are residents' rooms decorated with their personal belongings? What personal belongings are allowed?*

QUESTIONS TO ASK

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- Is an outdoor area available to the residents? Is this area secure, while providing residents a place to walk and a place to sit?*

Staff and Nursing Staff/Resident Ratios

Almost half of the SCUs in Oregon have a registered nurse as the unit coordinator. Some units are administered by a team of professionals, a certified nursing assistant, or a variety of individuals experienced in long-term care of the elderly.

The number of nursing staff compared to the number of residents is called the *nursing staff/resident ratio*. Because more staff are needed to work effectively with dementia patients, higher staff/patient ratios are one of the most common characteristics of SCUs.

Nursing staff/resident ratios in Oregon SCUs vary widely. In 1992, the average ratio of nursing staff to residents during the day was one staff person to six residents, with a range of 1-5 to 1-12. During the evening, the staff ratio averaged one to eight. Night staff ratios ranged from 1-5 to 1-25, with an average ratio of 1-15. These ratios apply only to nursing staff and do not reflect that some units have activity assistants, social workers, and therapists who may be on the unit for part of the day and/or evening.

The relatively similar staff ratios during the day and evening hours reflect the daily care needs of residents. Heightened activity in the late afternoon and early evening is common to some individuals with dementia.

Q QUESTIONS TO ASK

- What is the staff/patient ratio on the SCU? How does this vary during the day, evening, and night?*
- How do these compare to staff/patient ratios in the remainder of the facility?*

Staff Characteristics and Training

Recruiting and training of staff for SCUs presents unique challenges. Staff must be committed to the unit's approach and be able to work positively with the special needs of dementia residents. In 1992, approximately 80 percent of the SCUs in Oregon noted that they use special criteria to select staff. Eighty percent of the SCUs also reported that staff were assigned only to the special care unit and did not work in other areas of the facility.

SCUs sought staff with an interest in Alzheimer's disease, patience, a sense of humor, flexibility, a calm approach, and respect for the dignity of the residents.

The Alzheimer's Association recommends that staff training include:

- understanding Alzheimer's disease and related dementias;
- communication with Alzheimer's/dementia residents;
- adaptations for a supportive environment;
- techniques for interactions and interventions with residents and families;
- common behavioral problems and behavior management techniques; and
- therapeutic interventions and activities such as exercise and sensory stimulation.

In Oregon, more than 50 percent of SCUs provide more hours of training for SCU staff than for other facility staff. Most of this training focuses on the special needs of those with dementia.

When investigating care facilities, ask about the staff's training and experience with dementia. The unit coordinator should be able to summarize the staff's experience and training.

- Who is the person in charge of the SCU? Is this position his/her only responsibility or is his/her time divided between the unit and other positions, such as nursing or social services? Does it appear that this person has adequate time to supervise the SCU?*
- What personal characteristics does the unit look for in staff members? What experience does the staff have with persons with dementia?*
- How many hours of training does the staff receive before working on the SCU and what does this training involve?*
- How often does staff receive additional training while working on the unit?*

Q QUESTIONS TO ASK

Philosophy of Care and Goals

As part of new Oregon state regulations, each special care unit must have a written statement of its philosophy and goals. Ask the administrator of the facility or the coordinator of the unit to discuss these with you. Staff on the unit should know these as well.

A *statement of philosophy* reflects the attitude of the owners, management, and staff regarding the development and operation of the SCU. For example, a statement of philosophy should include:

- residents will be encouraged to function at the highest possible level; and
- residents will be treated with dignity and respect.

The *goals* of the unit describe how the facility staff carry out the philosophy. These goals will include specific plans for how the staff will assist the resident to be independent, productive, and active both mentally and physically. Look for goals such as these:

- improving the quality of life for the cognitively impaired residents;
- offering residents with cognitive impairments separate spaces within the facility to meet their psychosocial needs;
- providing a safe, clean, supportive environment;
- safeguarding residents' rights and dignity;
- providing an activity program specialized for adults with dementia.



QUESTIONS TO ASK

- What is the philosophy of care? What are the specific goals for care?*
- Can the staff and the unit coordinator clearly state the goals and philosophy of the unit?*

Resident Services

Resident care policies

Resident care policies are required by law and provide specific guidelines for the care of residents in the unit. These include policies regarding admission, discharge, transfer, use of restraints, or other care issues. Ask the administrator or unit coordinator to share these policies with you.

Admission

Each SCU in Oregon must have admission criteria. Most facilities use several methods for determining whether a prospective resident can benefit from placement in an SCU. In 1992, almost every Oregon SCU required a physician's diagnosis of dementia and more than 80 percent required the family's permission for admission. About 60 percent of SCUs also measured the prospective resident's "functional ability," that is, his/her ability to perform the activities of daily living such as bathing, eating, and toileting. This measurement, if used, should be readministered periodically to adjust the program to the resident's changing needs.

Two-thirds of the units responding to the state survey in 1992 admitted only residents who are ambulatory (that is, not in wheelchairs). One-half would not admit residents who exhibited certain aggressive behaviors. A few also had a minimum age requirement.

- What are the criteria for admission to the SCU? Request a written copy of the criteria.*
- Who determines whether a person meets these criteria?*
- Is there a trial period on the unit?*

QUESTIONS TO ASK

Transfer and Discharge

New Oregon state regulations require that each SCU have clearly defined discharge policies. The 1992 survey found that the most common criterion used for discharge by SCUs in Oregon was violent or abusive behavior which may cause danger to the resident or to others. About 70 percent of SCUs used this criteria; 70 percent also discharged residents when their physical care needs became too great.

If the level of care needed is not available on site, facilities may discharge residents from the unit to another area of the same facility or to another facility. Usually this happens when the resident becomes non-ambulatory, is unable to feed him/herself, or needs intravenous medication or other medical

life supports. About 25 percent of facilities cited other discharge criteria (such as inability to pay with private funds), so it is important to find out what discharge criteria are used.

QUESTIONS TO ASK

- If the SCU is part of a larger facility, what are the criteria for a transfer from the SCU to the other sections of the facility? For example, if a resident is to be transferred elsewhere in the facility, who determines this? How is this done?*
- What are the criteria for complete discharge from the SCU and from the facility? Can the resident be discharged for displaying behaviors that are symptoms of dementia such as wandering, combativeness, abusive language, bowel or bladder accidents, or other behaviors? Who determines when discharge is needed and how is this done?*
- How is the family or guardian involved when a decision is being made to transfer or discharge a resident from the SCU? How long do the individual and family have before the move occurs?*

Family Involvement

Families are a valuable asset to the staff and can identify the resident's history, routine behaviors, and special likes and dislikes.

The most common mechanisms used by dementia units in Oregon for family interaction with special care units are family involvement in care planning and care giving. About 93 percent of facilities responding to the 1992 survey involved families in care planning and care giving.

Many SCUs involve family and friends in the care given to residents. Families and friends can help the resident with dressing, eating, walking, and organized activities. Families and friends should participate at a level that feels comfortable.

Ask about visiting in the facility. Residents have a right to visitors at any time, but because of the special needs of some residents, the facility or unit may discourage visiting during certain times of the day or night.

In 1992, more than 50 percent of Oregon SCUs had a designated staff person who served as the link between the unit and families. Almost half of the units also offered a support group for families and provided educational opportunities for family members who wanted to learn more about dementia.

About one-third involved families in other ways, including newsletters, family councils or committees, and “buddy systems” for residents’ families.

Q QUESTIONS TO ASK

- How will the family/guardian be involved in planning the care of the resident?*
- What are the opportunities or expectations for family participation in care giving? If a family cannot participate, what alternatives are there to enable the resident to take part in activities and receive needed support?*
- Are family support services provided within the facility? If not, can the facility inform you about support services in the community?*
- What are the preferred visiting hours?*
- Is there a designated staff person who works specifically with families? Who is this? Who should be contacted if this person is not available?*
- What is the policy for notifying the family/guardian when there is an incident which could be potentially harmful to the resident or others?*
- Does the staff contact the family/guardian if the resident has episodes of difficult behavior? Does the staff welcome information from the family regarding possible reasons for the behavior?*
- How is the family/guardian notified when there is a significant change in the physical, mental, or social status of the resident?*

Activities of Daily Living

One goal of a specialized dementia unit should be the maintenance and support of each resident at his or her highest possible level of functioning. Assistance, care, and therapy should be offered that encourage each resident to perform independently or with the least possible assistance from staff.

For example, residents who have some trouble getting dressed might still be encouraged to choose their own clothing. Clothing with simple fasteners can promote independence. Some residents may be able to brush their own teeth if supervised and “talked through” the steps. Promoting independence in such activities of daily living helps residents maintain skills and self esteem.

Staff should allow adequate time and provide verbal prompting for residents who are capable of some self-care.

There should be a general schedule showing the *order* or sequence of activities although specific times are *not* necessary. Whatever the schedule, staff should be flexible in adapting to the changing needs of residents. For example, many units do not insist on meal times for residents who prefer to eat throughout the day. In this case, snacks are provided as necessary to ensure proper nutrition. Other facilities allow residents as much time as needed to complete a meal or other activity.

Observe how the unit staff deals with behavior of residents. This will reflect how well the staff is trained in the special needs of persons with dementia. Ask the staff to describe how they would respond to behaviors that your friend or relative currently displays.

SCUs should provide an environment where the use of physical restraints can be minimized. Recent federal legislation makes it increasingly difficult to justify the use of restraints to control behavior. SCUs discourage the use of physical restraints to manage difficult behavior. Still, there are times when the use of a physical restraint may be appropriate. When this is the case, an authorization order must be obtained from the resident's physician and the resident, and a family member or the guardian must be consulted and agree to the restraint.

Psychotropic medications, such as tranquilizers, are sometimes used to treat specific symptoms of dementia. Ask the staff or the unit coordinator under what circumstances such medications are used.

QUESTIONS TO ASK

- How are activities of daily living managed?*
- What is the routine for activities of daily living (ADLs) on the unit?*
- What methods does staff use to manage behavior of a resident?*
- How often, if ever, are physical restraints used to control behavior? Under what circumstances are they used?*
- How are psychotropic drugs such as tranquilizers used on the SCU?*

Therapeutic Programs and Care Provision

Activities Programs

Short attention span, physical agitation, and memory loss present special challenges for activity programming for persons with dementia. According to the Alzheimer's Association, an organized program of group and individual activities should be available to residents throughout every day and evening. All residents should be encouraged and enabled to participate.

Special care units across the country are continually trying new activities for those with dementia. The facilities responding to the Oregon survey in 1992 reflected this trend. More than 20 types of activities were reported, including physical exercise, music, crafts, pet therapy, parties, and religious services.

Some facilities also are experimenting with less "structured" activities by providing more activity assistants to work with one or two residents to keep them involved, safe, and comforted as their needs change throughout the day. All SCUs should provide "age appropriate" activities that build on the interests of older adults.

Other Therapeutic Services

In addition to a therapeutic approach to activities of daily living and recreational activities, over half the SCUs in Oregon offered occupational therapy, physical therapy, and speech therapy. Ambulation therapy in which a resident is encouraged or assisted to walk was offered by 85 percent of the SCUs. Over 90 percent offered bowel and bladder training programs for residents with incontinence problems. Such therapies were most common in intermediate care nursing facilities and residential care and assisted living facilities that serve persons with higher levels of functioning.

- What individual and group activities and therapies are offered? Do these activities provide the opportunity for the resident to feel useful? productive? to use past skills? Do the activities allow all residents to participate at whatever level they are able? Are the activities age-appropriate?*
- Who is responsible for activity programming? How much of that individual's time is devoted to the dementia unit? What are the background and knowledge of the person who develops, organizes, and conducts the activity program?*
- In what ways are other unit staff involved in activities?*

Q QUESTIONS TO ASK

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- Are families encouraged to participate in activities?*
 - What types of therapy are offered on the unit? For example, are incontinence management, physical therapy, speech therapy, ambulation assistance, and other therapies available in the SCU?*
 - Are the activities and therapeutic support your relative needs available? As patients' needs change, how are activities or therapies changed?*

Cost of the Unit Care

Most special care units charge a higher rate per day for care delivered in the unit than the rest of the facility. For example, if the nursing home is licensed as an intermediate care facility and will charge a rate based on this designation, costs in the SCU likely will be higher than the standard intermediate care rate. If costs are higher, ask the administrator what additional services are provided for this higher fee. The facility should provide written information on all rates, charges, the resident's obligation regarding payment, and refunds.

Medicaid is a joint federal-state program that provides financial support for persons who are unable to pay the costs of care. Often persons who enter nursing facilities exhaust their resources and become eligible for Medicaid support. Ask if the unit accepts Medicaid reimbursement. In 1992, 80 percent of the SCUs in Oregon reported they accepted Medicaid reimbursement. If the facility does not accept Medicaid, ask what options exist for care should the resident's funds be depleted.

Q **UESTIONS TO ASK**

- What is the SCU's daily rate and what specific services are included? How does this daily rate compare to that provided elsewhere in the facility?*
- What specific services are not included in the daily rate?*
- What is the facility's grievance procedure for addressing disagreements with any charges?*
- Does the facility participate in the Medicaid program? If a private pay resident's funds are depleted, what are the options for continued care in the SCU or larger facility?*

Summary

No one kind of care perfectly suits the needs of everyone with dementia. Care for persons with dementia is a rapidly changing field with new techniques being tried every day. Special care units are one such new approach.

A special care unit should exhibit the same positive features of any good care facility. In all long-term care facilities, residents should receive respect and loving care. The environment should support their fullest level of activity and functioning. Signs of such care include providing affection and personal attention for residents and treating residents like adults. The staff should be well trained to meet the diverse needs of the residents. These characteristics can exist in facilities whether or not they have SCUs.

Additional Resources

For additional information in Oregon, contact:

Program Assistance
State of Oregon Senior and Disabled Services Division
Human Resources Building
500 Summer St. NE
Salem, OR 97310-1015
503-378-3751

Lists of facilities, facilities' records of compliance with state regulations, and general information on levels of care.

Alzheimer's Association
Columbia-Willamette Chapter
1015 NW 22nd Ave.
Portland, OR 97210-3079
503-229-7115

Information on special care units, Alzheimer's disease, family support programs, and other chapters located throughout the state. A particularly relevant publication is "Selecting a Nursing Home with a Dedicated Dementia Care Unit."

Oregon Long Term Care Ombudsman Program
2475 Lancaster NE
Building B, Suite 9
Salem, OR 97310
503-378-6533
1-800-522-2602

Information on facilities; the Ombudsman Program receives and investigates complaints made by residents or families about long-term care facilities in Oregon.

For Further Reading

In July 1992 the OSU Extension Service publications warehouse was destroyed by fire. We are replacing our supplies. The publications listed below may be available in the office of the OSU Extension Service that serves your county. Check with that office for current prices.

You also may call Agricultural Communications at Oregon State University, (503) 737-2513, to learn the availability and current price of the publications.

Aging Parents: Helping When Health Fails, PNW 246, 50¢

Alcohol Problems in Later Life, PNW 342, 75¢

Coping with Caregiving: How to Manage Stress When Caring for Elderly Relatives, PNW 315, 75¢

Depression in Later Life, PNW 347, \$1.50

Families and Aging: A Guide to Legal Concerns, EC 1221, \$1.25

Helping Memory-Impaired Elders: A Guide for Caregivers, PNW 314, 50¢

Planning in Advance for Health Care Decisions, EC 1375, 50¢

Talking to Your Family Doctor About Difficult Health Care Decisions, EC 1386, \$1.25

Ordering Instructions

If you would like additional copies of EC 1425, *An Oregon Guide to Special Care Units for Patients with Dementia*, send \$1.25 per copy to:

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Agricultural Communications
Oregon State University
Administrative Services A422
Corvallis, OR 97331-2119

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