

DEMENTIA CARE

4.P. Dementia Care

A person-centered dementia care program values and fosters a dynamic culture that supports a partnership among persons served, families/support systems, and providers. Leadership recognizes that dementia care is a maturing, challenging, and forward-thinking field. It commits to providing the supports, resources, and education needed to stay current while enriching and optimizing the:

- Function and quality of life of persons served.
- Strengths of persons served.
- Capabilities of personnel.
- Performance of the program.
- Partnerships with families/support systems.

Through ongoing communication and assessment processes, the program demonstrates that it:

- Knows the histories, preferences, abilities, interests, skills, talents, and ongoing needs of persons served and recognizes and anticipates that these change over time.
- Bridges the person's past, present, and future.

Through these processes, persons served maintain their dignity and preserve their selfhood.

Leadership recognizes personnel's unique needs, abilities, interests, skills, and talents. It creates and supports a learning culture that provides teaching, coaching, modeling, supervision, and evaluation. Leadership oversees the evaluation of this learning culture in its performance improvement system.

Leadership creates an environment:

- In which persons served and personnel can thrive.
- That cultivates, supports, and maintains relationships.
- That maximizes function and optimizes independence.

Leadership maintains a safe physical environment for both personnel and persons served. Through leadership's attention to accessibility, usability, and appropriate assistive technologies, persons served maximize their functioning and optimize their independence as long as possible.

The program's corporate social responsibility includes its efforts, activities, and interests in integrating, contributing to, and supporting increased awareness of the preferences, abilities, interests, skills, talents, and ongoing needs of persons with dementia and their families/support systems to. The program is committed to increasing the awareness of the needs of the persons served to regulators, legislators, educational institutions, payers, and the community at large.

Applicable Standards

All Dementia Care Programs must meet Standards 1.–23.

An organization seeking accreditation as a Dementia Care Program must also meet the program description and standards for at least one of the following programs:

- Adult Day Services
- Aging Services Network
- Assisted Living

- Continuing Care Retirement Communities
- Person-Centered Long Term Care (Nursing Home) Communities

1. **Leadership demonstrates a partnership approach to person-centered dementia care through the provision of resources and education to:**
 - a. Persons served.
 - b. Personnel.
 - c. Families/support systems.
 - d. Other stakeholders as appropriate.

Intent Statements

Education of the team and the availability of resources are essential components for the provision of quality dementia care. The program’s leaders provide resources such as human resources and supplies, as well as the needed education to support a unified approach to care for each resident in the program.

Examples

Leadership might include owners, department heads, and managers—those who have control of resources and participate in program planning.

Other stakeholders may include contract personnel, clergy, vendors, consultants, and volunteers. Leadership in many organizations provides opportunities for those living in the external community to better understand dementia care through resources and education.

Through a partnership with leadership, personnel and family members learn to adapt to the needs of persons served rather than expecting them to adapt to theirs. One of the ways these individuals may comprehend how the person served views the world is through a partnership based on regular communication.

Survey Preparation Questions

1. How does leadership demonstrate that it has provided resources to support a partnership approach to dementia care to:

- Persons served?

- Personnel?

- Families/support systems?

- Other stakeholders as appropriate?

- How does leadership demonstrate that it has provided education to support a partnership approach to dementia care to:

- Persons served?

- Personnel?

- Families/support systems?

- Other stakeholders as appropriate?

2. Leadership supports program strategies and interventions that are based on current research, peer-reviewed scientific and health-related publications, clinical practice guidelines, or expert professional consensus.

Intent Statements

The field of dementia care is continually changing, bringing new and better ways to support persons with dementia. Leadership demonstrates that it ensures that the program strategies used reflect current research and literature.

Examples

Current research includes the following topics:

- Association between depression and behavioral symptoms
- Persons served receiving treatment for pain
- Dining
- Mobility limitations
- Low fluid intake

- There is an association between grooming and personnel perception of residents' quality of life.

- Quality of life

- Family involvement

- The impact of Pick's disease and appropriate caregiver techniques

It is known that individuals with Pick's disease do not respond well to verbal instructions; therefore, the caregiver may turn on the shower and then direct the person served with hand motions to move into the shower and bathe.

Individuals with alcohol-related dementia may be more susceptible to sudden outbursts. Personnel should be aware of non-confrontational caregiving techniques.

Frontline caregivers benefit from receiving information stemming from research findings. Some programs provide periodic inservice programs, which focus on some of the latest techniques in dementia care. Feedback from frontline caregivers should also be shared when they develop their own techniques that result in improving care for persons served.

Leadership may provide information to personnel about current practices through a variety of methods, including inservice education, opportunities to attend conventions and meetings that keep personnel current, availability of journals/articles that address these issues, and opportunities for sharing information learned among personnel.

Survey Preparation Questions

2. How does leadership demonstrate that it supports program strategies that are based on current research, literature, and professional consensus?

What interventions, programs, or systems can you describe that have been instituted as the result of knowledge of current research?

What systems does your program have in place to become aware of current research and practices to advance dementia programming?

3. The program identifies:
- The individual who has the responsibility and authority to manage the dementia care program.
 - The skills and competencies required to perform as a dementia care program manager.

Examples

A program may have created a position description outlining the responsibilities, skills, and competencies of the program

manager. A program might decide that previous experience working with persons with dementia is a requirement for the manager; this could then be included in his/her skills and competencies.

Survey Preparation Questions

3. Describe how your program identifies the individual who has the responsibility and authority to manage the dementia care program.

What are the skills and competencies the program has identified as necessary for the dementia care program manager?

4. If the organization has a physician who provides medical direction for the dementia program, he or she:
- Is board certified in his/her specialty.
 - Demonstrates appropriate experience and/or training with the population served.
 - Demonstrates at least one of the following annually:
 - Participation in at least one meeting per year of a regional or national organization that includes sessions on the management of issues in the care of persons with dementia, with evidence of having obtained credit for continuing medical education.

- (2) **Presentation of an abstract or paper to a regional or national organization on dementia issues.**
- (3) **Publication of an article on dementia issues in a peer-reviewed journal.**
- (4) **Membership in an organization or special interest group at a regional or national level whose primary focus is on dementia issues.**

If *yes*, describe his/her education/experience in dementia care.

Describe how you determine that your program medical director remains current on issues related to dementia care (e.g., education, research, and publication)?

Intent Statements

If a physician provides direction to the dementia care program, he/she has and continues to demonstrate experience and/or training as well as ongoing engagement in the dementia care field. It is expected that the physician is board certified in his/her specialty.

Examples

The medical director of the “xyz” dementia care program is board certified in geriatric medicine and is a certified medical director. The medical director regularly makes presentations at meetings and writes for journals on issues related to dementia care.

A medical director is board certified in internal medicine and has worked with residents with dementia for the past ten years. This individual is active in and volunteers with the local Alzheimer’s Association. Annually, he/she attends medical education programs that present information on current dementia care issues.

Survey Preparation Questions

4. Do you have a physician who participates in the medical direction of your dementia care program?

Yes No

5. **Ongoing opportunities to share talents, mentor, and teach are provided to:**
- a. **Persons served.**
 - b. **Families/support systems.**
 - c. **Personnel.**
 - d. **Other stakeholders as appropriate.**

Intent Statements

Persons with dementia, as well as families, personnel, and other stakeholders, have opportunities to share their talents as well as inform others about caring for persons with dementia.

Examples

Persons served will feel the rewards of care that maximize their abilities, focus on their strengths, and enhance their quality of life. Using information from the assessment, personnel have identified each person’s abilities and strengths and finds ways for him/her to share, mentor, and teach. The program’s plan for each person served is ability centered, not focused on disability.

A dementia care program may have contact with the local Alzheimer's support group and may encourage persons in the early stages of the disease to participate in the orientation of personnel working in the program.

One of the persons served in the dementia program was a horticulturist. She may be included in planning for the plants in the adult day center and for the vegetable garden in the neighboring assisted living program.

Families/support systems may participate in orientation and ongoing education to demonstrate improving communication techniques. Families/support systems have access to activity supplies and may share their talents with residents during visits. Examples of sharing talents may include facilitating access to computers, music, art, puzzles, flash cards, and other resources.

Volunteers from the local Alzheimer's Association may participate in the orientation of personnel working in the program. These volunteers may also provide educational events for families of persons served in the dementia care program.

Survey Preparation Questions

5. Describe how the program encourages talent sharing, mentoring, and teaching by:

- Persons served.

- Families/support systems.

- Personnel.

- Other stakeholders involved as appropriate.

6. Leadership fosters a continuous learning environment that:

- a. Recognizes and respects the personnel's individual:
 - (1) Learning styles.
 - (2) Needs.
 - (3) Strengths.
- b. Provides and evaluates:
 - (1) Teaching.
 - (2) Coaching.
 - (3) Modeling.
 - (4) Supervision.
 - (5) Feedback.
- c. Measures the effectiveness of the techniques used in the learning environment against a performance target.

Intent Statements

Education of personnel who care for and serve residents with dementia has been identified as a key component. Leadership ensures that the program has processes in place for initial and ongoing education designed to meet the needs of each staff member.

Examples

The dementia care program identifies the best way for each of its personnel to learn. For some it is in a classroom; for others it is a hands-on approach with a return demonstration; for others it is self-directed, computer-based education; and for others, it is a group discussion. Leadership ensures that personnel receive the education they need in the style best suited to their needs.

There may be opportunities for personnel to evaluate the program's teaching mechanisms, how they believe they have been coached, and the feedback they have received from their supervisors. Leadership models the desired behaviors for personnel.

Direct care personnel might need to make on-the-spot decisions that have traditionally been first cleared with their supervisor. Supervisors might need ongoing coaching to help them empower and support the direct care personnel to be decision makers.

Persons served, families/support systems, and personnel may be involved in the creation of a curriculum as well as in the initial and ongoing educational initiatives. Direct care personnel might have a more in-depth curriculum than other personnel who work in the program.

Examples of the content that may be covered in a dementia program orientation include:

- Normal aging—cognitive, psychological, and functional abilities of persons who are older.
- Definition, diagnosis, and description of dementia and how it differs from delirium and depression.
- Explanation of dementia and related disorders, progression, stages, and individual variability.
- Communication techniques.
- Behavior symptoms and how to approach persons served when they display challenging behaviors.
- The role of personality and environmental factors in behavioral symptoms of dementia.
- The philosophy of dementia care, principles of ethical decision making, and the interdisciplinary approach to care.
- Working with families/support systems.
- Resources for persons served and their families/support systems.
- Stress reduction techniques for direct care personnel.

Potential measures of the effectiveness of learning techniques may include:

- Assessment of learning styles, needs, and strengths.
- Success of coaching.
- Appropriateness of level of supervision.
- Feedback regarding quality, quantity, or access to learning techniques.

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Survey Preparation Questions

6. Demonstrate how your program recognizes and respects the individual learning styles/needs of personnel.

Describe how you provide for:

■ Teaching.

■ Coaching.

■ Modeling.

■ Supervision.

■ Feedback.

Describe how you evaluate:

■ Teaching.

■ Coaching.

■ Modeling.

■ Supervision.

■ Feedback.

Describe the way you evaluate the effectiveness of techniques used in the learning environment.

What are the performance targets you have set?

7. Leadership creates a culture that cultivates, supports, and sustains relationships that are meaningful to:
- Persons served.
 - Families/support systems.
 - Personnel.

Intent Statements

Research demonstrates that for people with dementia, well-being is a direct result of the quality of relationships they enjoy with those around them. Leadership is responsible for creating the environment in which these relationships occur and are sustained.

Examples

Leadership supports consistent staffing. Leadership attempts to minimize the use of agency personnel while reducing turnover and absenteeism to create the capacity for consistent staffing.

Leadership supports the nursing, activity, and dietary departments to ensure that personnel working with residents in the dementia program are consistent. Leadership and managers work together to minimize use of agency personnel while reducing turnover and absenteeism to create the capacity for consistent staffing.

Survey Preparation Questions

7. Describe how leadership creates a culture that cultivates, supports, and sustains relationships among persons served, families/support systems, and personnel.

8. To improve and maintain the learning and growth of personnel and enhance recruitment and retention, the program provides:
- Opportunities for career development.
 - A forum for personnel to:
 - Recognize successes.
 - Acknowledge challenges.
 - Solve problems.
 - Participate in care planning.
 - Participate in program development.
 - Training on gathering information about the person served in the following areas:
 - Important memories and favorite stories.
 - The person's life routines.

- (3) **The person’s life roles.**
- (4) **The person’s family.**
- (5) **The person’s history, including:**
 - (a) **Social.**
 - (b) **Spiritual.**
 - (c) **Health.**
 - (d) **Sexual.**
 - (e) **Emotional.**
 - (f) **Psychological.**
 - (g) **Behavioral.**
 - (h) **Vocational.**
 - (i) **Cultural.**
 - (j) **Educational.**
 - (k) **Recreation and leisure.**

d. Training on sharing information gained with team members.

Intent Statements

The program offers career development opportunities for personnel and provides opportunities for them to work together to identify the challenges they face, share solutions, and recognize their successes. Personnel receive education on how to obtain information about each person served, which gives them insight into caring for the person served as an individual.

Examples

Dementia care is continually evolving. Providers are dedicated to presenting opportunities for ongoing personnel education and career development.

To support and encourage personnel growth and development, career ladders may be established.

If obtaining information from a person served or family/support system is difficult, personnel may obtain information through other sources such as medical or other types of records, or by observing the response of the person served to particular approaches to care.

Knowing the morning rituals of the person served, such as if he/she prefers coffee or tea and how much sugar in it;

his/her preferred time for waking; and how and when he/she wishes to be bathed may contribute to the insight needed in caring for each person served.

Understanding the culture of the persons served may provide clues as to how to care for them. However, personnel should have knowledge about the unique aspects of the cultures represented in the program.

Personnel identify potential triggers for behaviors and emotional symptoms of the person served such as agitation and depression. When these triggers are present, personnel may use environmental and behavioral strategies to modify their impact.

Personnel are provided opportunities to express their reactions to the decline of a person served over time and his or her eventual deaths.

When gathering information about persons with dementia, direct care personnel should be taught to be aware of those areas that might be sensitive to persons served.

Survey Preparation Questions

- 8.** Describe what opportunities this program offers for career development.

Describe ways in which this program provides a forum to:

- Recognize successes.

- Acknowledge challenges.

- Solve problems.

- Participate in care planning.

- Participate in program development.

How does this program educate the personnel on gathering information about the person served regarding:

- Important memories and favorite stories?

- The person's life routines?

- The person's life roles?

- The person's family?

- The person's history, including:

- Social?

- Spiritual?



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- Health?

- Vocational?

- Sexual?

- Cultural?

- Emotional?

- Educational?

- Psychological?

- Recreation and leisure?

- Behavioral?

How does this program educate the personnel on sharing information gained with members of the team?

9. **On an ongoing basis, personnel demonstrate the ability to use observations of behavioral events as opportunities to better:**
 - a. **Understand persons served.**
 - b. **Meet the needs of persons served.**

Intent Statements

The behavior of persons served may be seen as a form of communication and an expression of preference. Behavioral events are a way of communicating and might therefore be the person served trying to meet his/her own needs. Personnel should demonstrate their ability to understand the behaviors of persons served and their impact on the needs of persons served.

Examples

The person served repeatedly refusing a certain food might be an expression of their dislike of the food.

Poorly managed pain may result in behavioral symptoms and lead to unnecessary use of psychotropic medications. Personnel may observe persons served for verbal or physical expressions of pain. These expressions may include sighing, grimacing, moaning, slow movement, rigid posture, and withdrawing extremities during care.

Common precipitants of behavioral events may be:

- Environmental factors, such as unpleasant stimuli or lack of structured activities.
- Direct care personnel actions—personal care may be seen as a threat; direct care personnel are not consistent.
- Medical problems, such as pain, fatigue, constipation, medications, or untreated disease.

- Untreated mood disorders, such as anxiety or depression.
- Disease-related predisposing factors, such as delusions, hallucinations, poor impulse control, amnesia, and aphasia.

Survey Preparation Questions

9. Provide examples of how personnel demonstrate their ability to use observations of behavioral events as opportunities to better:

- Understand persons served.

- Meet the needs of persons served.

Describe the education that personnel have received to help them understand behavioral events to meet the needs of persons served.

10. **On an ongoing basis, personnel in collaboration with other members of the team:**
 - a. **Assess the behavioral event by:**
 - (1) **Observing the person served.**
 - (2) **Describing the behavioral event.**

- (3) **Understanding the behavioral event:**
 - (a) **From the perspective of the person served.**
 - (b) **From the perspective of personnel.**
 - (c) **From the perspective of the family/support system.**
 - (d) **From the perspective of other persons served.**
 - (e) **As communication on the part of the person served.**
- (4) **Analyzing the potential causes of the behavioral event.**
- b. **Determine the appropriate approach, treatment, and/or supports necessary for managing behavioral events based on their observations and assessments.**
- c. **Implement the appropriate approach, treatment, and/or supports based on the analysis of behavioral events.**
- d. **Assess the results.**
- e. **Share the information learned with:**
 - (1) **The person served.**
 - (2) **Other personnel.**
 - (3) **Families/support systems.**
 - (4) **Other relevant stakeholders.**

Examples

Examples of questions for analysis of behavioral events are:

- Why is this behavior occurring in this person at this time?
- Is this behavior consistent with the past?
- What needs or desires are evident in this behavior?
- What is occurring in the environment, in interactions with this person, and within this person at the time of the behavioral event?
- How is the person experiencing this event right now?

- Does the behavioral event reflect changes in the person's physical/medical status or the effects of medications?

- What are the response options?

Personnel are instructed in how to obtain information from families so that they are better able to interpret behavioral events. Sharing information among all involved in care is essential if consistency of response is to be maintained. Such communication will ensure that antecedent behaviors to these behavioral events are documented so that the efficacy of interventions may be evaluated and revised or shared.

Organizations may use experts from the Alzheimer's Association, other national or local resource groups, and the local university to assist them in analyzing events and creating solutions.

Survey Preparation Questions

- 10.** Provide an example of how personnel go through the following steps to uncover the meaning behind a behavioral event:

- Observe the person served

- Describe the behavioral event

- Understand the behavioral event:
 - From the perspective of the person served
 - _____
 - _____
 - _____
 - From the perspective of personnel
 - _____
 - _____
 - _____
 - From the perspective of the family/ support system
 - _____
 - _____
 - _____
 - From the perspective of other persons served
 - _____
 - _____
 - _____
 - As communication on the part of the person served
 - _____
 - _____
 - _____
- Analyze the potential causes
 - _____
 - _____
 - _____
- Implement the appropriate approach, treatment, and/or supports
 - _____
 - _____
 - _____
- Assess the results
 - _____
 - _____
 - _____
- Share the information learned with:
 - _____
 - _____
 - _____
 - The person served
 - _____
 - _____
 - _____
 - Other personnel
 - _____
 - _____
 - _____
 - Families/support systems
 - _____
 - _____
 - _____

- Other relevant stakeholders

How are personnel taught to carry out this process?

11. Activities for persons served:

- a. **Reflect their choices, preferences, and lifelong interests.**
- b. **Promote their:**
 - (1) **Personal growth.**
 - (2) **Enjoyment.**
 - (3) **Engagement.**
- c. **Enhance their self-esteem.**
- d. **Maintain their functional levels whenever possible.**
- e. **Provide opportunities for social relationships.**

Intent Statements

Choice should be one of the distinguishing features of a dementia care program. Routines should reflect choices of persons served.

Functional abilities of some persons served might appear to prohibit them from participating in desired activities. Creative solutions may be introduced to enable persons served to participate. New technologies may provide opportunities for individuals with sensory impairments to experience activities previously thought impossible.

Examples

Events, encounters, or exchange between persons served and personnel are potential activities. Personnel focus on what persons served can do, not what they are no longer able to do. Activities should focus on those things that provide meaning and purpose in the lives of persons served.

Persons served are encouraged to continue those activities that they enjoyed in the community to the extent possible and in a manner they can participate. Gender-specific activities should be considered to ensure that individual needs are addressed.

The activities that make up a person's daily experience should reflect, as much as possible, that individual's preferred lifestyle while providing a sense of usefulness, pleasure, success, and as normal a level of functioning as possible. Activities may be normal everyday things we do. To be meaningful, an activity should:

- Have purpose that the person served can appreciate.
- Be done voluntarily.
- Respect the individual's age and social status.
- Engage the individual's retained abilities.
- Offer an opportunity for success.
- Feel good.

Persons served have access to outdoor space, and caregiving personnel offer outside activities for persons served. Formal and informal exercise programs are provided to improve and maintain strength and stamina.

If we know that a person served has been a loner, seeking solitary pursuits, we would not plan activities for him/her that encouraged socialization and group participation. However, if a person served is known to have been gregarious and outgoing but is now unable to find a

comfortable social outlet, the goal may be to identify and pursue appropriate social experiences for him/her.

Incorporating activities that promote fluid intake can improve hydration. Activities could include consumption of popsicles, sherbet, fruit slushes, gelatin desserts, or other forms of fluid and having these items readily available to persons served. An example of a hydration-focused activity is a happy hour that may encourage fluid intake.

Additional examples of meaningful activities for those who are ambulatory as well as those who are not ambulatory could include having persons participate in making decorations for a party, giving massages, listening and singing to music, and storytelling.

Survey Preparation Questions

- 11.** How does the organization adapt care and services to schedules and needs of individuals rather than expecting that person to adapt to the organization's?

Describe how the activities in your dementia program:

- Reflect each person's choices, preferences, and life-long interests.

- Promote his/her:
 - Personal growth.

- Enjoyment.

- Engagement.

- Enhance his/her self-esteem.

- Maintain or improve his/her functional level, whenever possible.

- Provide opportunities for social relationships.

12. The usability of the environment:

a. Maximizes the functioning of persons served in the following areas:

- (1) Physical.
- (2) Cognitive.
- (3) Sensory.
- (4) Social.

b. Optimizes their independence.

Intent Statements

The physical environment and design features support the functioning of the persons served, maximize functional abilities, promote safety, and encourage their independence.

Examples

These examples of environmental design illustrate ways in which the environment may be structured to enhance functioning and well-being:

- Maximizing awareness and orientation
 - Keep signs simple and at eye level, with bright and contrasting colors.
 - Create purpose-specific rooms so persons served always know what to expect.
 - Make key destinations easily visible (e.g., dining room and bathroom).
 - Create aromas to signal when it is mealtime.
- Ensuring safety and security
 - Public or shared areas are easily monitored by caregiving personnel.
 - Decrease the visibility of the door that persons served should not use.
 - Floors should not be highly polished, appearing slippery.
 - Minimize sharp color contrasts in flooring.
- Use locking or alarm devices for exit doors.
- Separate power and timer controls for potentially hazardous equipment.
- Providing privacy
 - Try to provide something more substantial than a curtain between beds. When persons lose opportunities to be alone, they tend to withdraw even when in larger groups.
 - For those in shared rooms, schedule times when they can be alone.
 - Knock and wait for a response before entering private rooms.
 - Provide small public rooms where privacy can be obtained, for example when families visit.
- Supporting functional abilities
 - Simplify clothing storage and provide extra lighting.
 - Use open basket storage systems if persons served no longer look in drawers.
 - Use large, easily visible sink faucet handles.
 - Locate a toilet adjacent to each public area.
 - Decorate the bathroom to look like home.
 - Minimize excess noise at meals.
 - Group individuals to support needs at mealtime.
 - Provide appropriate access to phones.
- Adjusting the amount of stimulation
 - Eliminate overhead public address systems.
 - Provide opportunities to regulate the amount of noise from items such as institutional support

- systems (ice machines), group activities, or disruptive vocalizations.
 - Minimize or eliminate strong negative odors.
 - Provide even lighting as much as possible.
 - When using patterns in fabric or on walls, be aware that the eye is drawn to strong contrasts in color and hue.
 - Providing positive quality stimulation
 - Be aware of individual preferences for music.
 - Increase or emphasize sounds from positive sources (laughter, meal preparations, pleasant conversation).
 - Decorate in ways that are culturally and socially meaningful to persons served.
 - Provide a variety of objects with varying textures for persons served to pick up and carry around.
 - Vary design and décor in different rooms.
 - Providing opportunities for personal control
 - Develop policies that enable the person served to choose where he/she wants to be.
 - Differentiate hallways.
 - Provide window treatments that can be adjusted by persons served.
 - Provide a variety of dining room table sizes.
 - Facilitating social contact
 - Provide seating in hallways or junctures of hallways where persons can sit and watch and talk about what is going on.
 - Set chairs at right angles to each other rather than side by side to make conversation easier.
 - Locate chairs near areas of interest to facilitate topics of conversation.
 - Create social spaces for different size groups using room design variations and furniture arrangement.
 - Maintaining self-identity
 - Encourage persons served to bring furniture and personal possessions as possible.
 - Vary the furniture in different rooms.
 - Encourage persons served and families/support systems to bring in furniture for shared public areas, being aware that personal chairs may sometimes cause territorial issues.
 - Adapting to stages of the disease
 - Recognize that sensory, cognitive, and functional capabilities of persons served vary according to the stage of their dementia and vary the environmental interventions based on the current functional capabilities of the person served.
- Elements in the physical environment that may create opportunities for maximization of function could be:
- Paths and walkways that encourage exploration and strolling.
 - Furniture groupings, such as tables and chairs that encourage stopping and spontaneous social interaction.
 - Interest points such as a fish tank or a window overlooking an active area that encourages observation.

- Workstations, both inside and outside, with interesting yet safe articles that promote individual or group activities such as:
 - A hat rack with a variety of interesting hats to try on.
 - A desk with an assortment of catalogues and magazines and files to review and sort.
 - A digging plot that persons served keep well turned and in which they can plant flowers and vegetables.

- Social

How does the program’s environment optimize the independence of individuals?

Survey Preparation Questions

12. Describe how various aspects of the program’s environment maximize the functioning of persons served in these areas:

- Physical

- Cognitive

- Sensory

13. The ongoing assessment process includes information about the person’s:

- a. History.
- b. Current status.
- c. Important memories.
- d. Favorite stories.
- e. Daily routines.
- f. Status in the following areas:
 - (1) Social.
 - (2) Spiritual.
 - (3) Health.
 - (4) Sexual.
 - (5) Emotional.
 - (6) Psychological.
 - (7) Behavioral.
 - (8) Vocational.
 - (9) Cultural.
 - (10) Educational.
 - (11) Leisure/recreational activities.
 - (12) Cognition.

Intent Statements

Ongoing assessment should reflect the unique features of dementia; therefore, it is essential that personnel conduct an assessment. Assessments should address

all aspects of the person with dementia so that personnel can understand his/her needs and wants. Families/support systems are important sources of information and are viewed as partners in this assessment.

Examples

Each person comes into the care situation with a lifetime of experiences, habits, prejudices, values, and roles that determine his/her individual needs and unique reactions to the situations and activities he/she is offered. To plan for care and services, it is essential that personnel gather such information.

Family members may help develop a “life story” of the person served, offering detailed background information about their life experiences, personal preferences, and daily routines. Request him/her to describe how he/she elicit cooperation regarding necessary care activities and include this in his/her plan.

Cognitive function usually parallels language. Assess language function by speaking with the person served.

- Persons who understand and speak in complete, fluent sentences have very high function.
- Persons who use sentences but tend to lose the flow of the conversation have moderate function.
- Persons with limited and low function understand and speak largely in single words and/or phrases.
- Very low function implies no language.

Families/support systems may provide information regarding the resident’s prior life, customary routines, preferences, behavior triggers, and results of attempted interventions. Persons served or their families/support systems may describe cultural traditions or interpret language, nonverbal interactions, and the meaning behind behaviors affected

by major life events (e.g., World War II, the Holocaust, the Great Depression).

During an assessment, personnel should focus on the individual’s current and life-long goals, lifestyle preferences, and ways to enhance life experiences and reduce the effect of impairments. For example, a person served who had been a night security guard “helps” the personnel in making rounds at night and tends to sleep better during the day.

Determine if the language spoken by the person served is his/her primary language.

While assessing food intake of the person served, personnel should observe for these warning signs:

- Difficulty chewing and swallowing
- Poor utensil use
- Refusing substitutions
- Low attentiveness to a meal
- Food uneaten during a meal

Personnel should discuss what they observed during the assessment and plan accordingly.

Survey Preparation Questions

- 13.** How do you determine, from the assessment, what each person served needs from the dementia care program?

Describe how you gather the following information about each person served:

- The person’s history

■ The person’s current status

- Health

■ Important memories

- Sexual

■ Favorite stories

- Emotional

■ The person’s daily routines

- Psychological

■ Status in the following areas:

- Social

- Behavioral

- Spiritual

- Vocational

- Cultural

- Educational

- Leisure/recreational

- Cognition

How do you engage the family/support system in this process?

- 14. The program's care and service delivery systems are:**
- a. Flexible.
 - b. Accessible.
 - c. Responsive to the needs of:
 - (1) Persons served.
 - (2) Families/support systems.
 - (3) Personnel.

Examples

Care should be flexible enough to adapt to daily changes in the needs and wishes of the person served. Communication among personnel, persons served, and the family/support system is key to keeping current.

Information regarding the assessment, the plan, and the life story of the person served is accessible to personnel. An example of information sharing is a slide show with the family/support system that highlights life events of the person served as well as his/her likes and dislikes. New personnel have an opportunity to view this slide show before they begin caring for the person served.

Survey Preparation Questions

- 14.** How is the program flexible, accessible, and responsive to the changing needs of persons served?

How is the dementia care program responsive to the needs of persons served, families/support systems, and personnel?

- 15.** The program seeks out and recognizes the advocate for the person served who is available and active in his/her life.

Intent Statements

CARF does not have any expectation regarding who fulfills this role. The number will depend on the size and type

of program. The program should demonstrate the process of identifying and verifying that the individuals who advocate on behalf of the person served are available and engaged with the person served.

Examples

Examples of seeking out and recognizing the advocate for the person served may include:

- Interviewing families/support systems of the person served.
- Facilitating the appointment of a legal guardian for the person served.
- Regularly reviewing the involvement of the person identified as advocate with the person served.

Survey Preparation Questions

- 15.** Explain the process of how the program seeks out and recognizes the individuals who advocate for the persons served.

- 16.** On an ongoing basis, the program shares information:

- a. With:
- (1) The person served.
 - (2) The family/support system.
- b. In a manner that is:
- (1) Supportive.
 - (2) Unbiased.

Examples

Families/support systems are kept informed of the medical status and prognosis of the person served through periodic meetings with the care delivery team in accordance with the preferences of the person served and applicable legal requirements regarding exchange of personal information.

Survey Preparation Questions

- 16.** Describe how the program demonstrates how it shares supportive and unbiased information with:

- The person served.

- The family/support system.

- 17.** The program/personnel considers and involves as a partner the family/support system, including its:

- a. Ability and willingness to support and participate in the plan.
- b. Composition.
- c. Interpersonal dynamics.
- d. Different methods of:
 - (1) Coping.
 - (2) Engagement.
 - (3) Communication.
- e. Expectations of the program.
- f. Educational needs.
- g. Responsibilities, including legal responsibilities.
- h. Identification of any unique financial, social, or cultural factors that might influence the program.
- i. Health status as the primary caregiver.

Intent Statements

The program should identify the strengths and/or barriers that the members of a family/support system bring that could contribute to their involvement as team members.

Survey Preparation Questions

17. Describe how your family/support system assessment considers:

■ The family/support system's:

- Ability and willingness to support and participate in the plan.

- Composition.

- Interpersonal dynamics.

- Different methods of:

- Coping.

- Engagement.

- Communication.

- Expectations of the program.

- Educational needs.

- Responsibilities.

- Legal responsibilities.

- Identification of any unique financial, social, or cultural factors that might influence the program.

- The health status of the primary caregiver.

18. The program provides or coordinates services for each family/support system as needed, including:

- a. Advocacy training.
- b. Counseling.
- c. Education.
- d. Support services.
- e. Reasonable accommodations.
- f. Assistive technology.

Examples

Families/support systems are able to participate in the caregiving routine as they desire.

Resources could be available to assist families/spouses coping with:

- Conflict.
- Feelings about placement.
- How the person with dementia is changing.
- Life changes.
- Stressful situations or issues.
- How to define a new caregiving or life role.
- Finding a support group or counselor.
- The progression of the disease.

- Movement to a different unit, level of care, or setting.

- Grief or loss.

To facilitate family/support system engagement, opportunities should be available to have families/support systems participate in activities.

Examples of opportunities for engagement could include:

- Calling bingo.
- Helping with the craft program.
- Reading to persons served.
- Arranging for community visitors.
- Orchestrating a musical event.
- Providing a manicure.

Families may be taught to advocate for elders in the community on their rights and payment for services or equipment.

Survey Preparation Questions

18. Describe how your program's provision or coordination of services for each family/support system includes:

- Advocacy training.

- Counseling/support services.

- Education.

- Support, including, but not limited to:

- Spouse-to-spouse interactions.

- Family-to-family interactions.

- Reasonable accommodations.

- Assistive technology.

19. The program facilitates collaboration in decision making through:

- a. **Opportunities for the sharing of information through:**
 - (1) **Meetings that are scheduled at the convenience of the family/support system.**
 - (2) **Informal exchanges.**
- b. **Accessible information.**
- c. **Time lines for the exchange of information.**
- d. **Identification of the level of understanding of the information presented by:**
 - (1) **The person served.**

- (2) **The family/support system.**

- (3) **Personnel.**

Examples

Between scheduled care planning meetings, a family/support system has requested to meet with personnel to discuss a change in the condition of the person served. The personnel responsible for the person served schedule a meeting time that is convenient for the involved stakeholders. Personnel work with the family/support system until they are certain they understand the implications of the plan.

A person served from your program is admitted for rehabilitation following a fractured hip. She is not participating in therapy and continually says she wants to go home. She has the potential to return to your program with the proper therapy. The family/support system is called to discuss how to encourage her to participate in the therapy regimen.

A person served in your program no longer meets the criteria. Personnel feel that it is time for this person served to transition to a skilled unit. The family/support system will have concerns about this move, so the individual responsible for the care of the person served schedules a meeting to discuss this with the family/support system.

In communicating with families/support systems that do not live near the program, the telephone, facsimile, e-mail, webcam, and other forms of communication are used to facilitate inclusion in decision making.

Efforts are made to ensure that all involved, including personnel, families/support systems, and persons served, understand the issues.

Survey Preparation Questions

19. Describe how your program facilitates collaboration in decision making through:

■ Opportunities for the sharing of information through:

- Meetings that are scheduled at the convenience of the family/support system.

- Informal exchanges.

■ Accessible information.

■ Time lines for the exchange of information.

Describe how personnel identify the level of understanding of the information presented by:

■ The person served.

■ The family/support system.

■ Personnel.

20. The program demonstrates:

- a. Knowledge of the legal autonomy of persons served.
- b. The provision of information to persons served and their families/support systems regarding appropriate changes in legal autonomy.

Intent Statements

A person might not possess the cognitive ability to make decisions in his/her own best interest. A surrogate might need to be assigned to make decisions regarding healthcare choices, financial decisions, or life care planning. Legal terminology might vary from state to state or province to province (i.e., healthcare power of attorney, power of attorney, and guard-

ianship). The program should be able to discuss how it addresses the issue of the legal autonomy of persons served.

Any limitation on a person's legal autonomy should be continued only as long as it is appropriate and necessary. The program should assist the person served and his/her family members/support systems to access resources, such as attorneys with expertise in this area who may assist with facilitating changes, if appropriate, in legal autonomy status.

Examples

Personnel obtain information at the time of entry into the program about the most current advance directive (e.g., durable healthcare power of attorney or living will) as well as preferences regarding palliative care when appropriate. This will ensure that the resident's wishes will be honored.

Survey Preparation Questions

20. Describe how your program demonstrates:

- Knowledge of the legal autonomy of persons served.

- The provision of information to persons served and their families/support systems regarding appropriate changes in legal autonomy.

21. The program demonstrates the ability to incorporate into the plan of care for those with end-stage dementia:

- a. A palliative approach to care.
- b. End-of-life care.

Examples

Individuals with severe and irreversible dementias might no longer be able to eat at the end of life and might need only comfort care. For example, they may have their mouths moistened and be given oral care.

When persons served are near the end of life, artificial nutrition and hydration might be withheld in accordance with their wishes/advance directives.

Persons served and their families/support systems should receive information about palliative care options, including hospice, when residents appear to have entered the final stages of dementia. Such signs could include the person's inability to walk without assistance, inability to sit up without support, inability to smile, unrecognizable speech, and swallowing problems.

The program should demonstrate an understanding of personal choice and implement programs to support these choices at the end of life. Programs should support the choices of persons served and should also encourage them to make these known to personnel.

Survey Preparation Questions

21. Describe how your program demonstrates an understanding of:

- A palliative approach to care.

- End-of-life care.

22. Persons served and their families/ support systems are afforded opportunities:

- a. For expression of final wishes concerning end-of-life issues.
- b. To honor wishes concerning end-of-life issues.

Intent Statements

Persons served, families/support systems, and personnel have opportunities to talk about end-of-life issues and participate in planning the memorial service and creating end-of-life protocols.

Examples

Families/support systems should be involved in the development of advance directives and in identifying the extent to which medical intervention is to be administered.

Whenever possible, no one dies alone. Support and presence is planned for each person served so that they do not die alone.

The person served and his/her family/ support system are interviewed about preferences for the dying process (i.e., five wishes, music, individuals present, preparation and notification, comfort items, and spiritual needs); care planning includes these preferences.

Memorial gardens may be developed outside on organization property in remembrance of those lost.

Memorials that reflect the person may be evident throughout the organization.

Do-not-resuscitate (DNR) orders are known and strictly adhered to. Efforts are made to clarify issues related to a person's end-of-life wishes to avoid any misunderstanding on the part of personnel and/or family/support systems.

Some organizations do not choose to have a memorial service, but they may provide opportunities for personnel to express their grief by supporting them so they may attend the funeral of the person served.

Survey Preparation Questions

22. Describe how your community:

- Makes expression of final wishes concerning life closure available to persons served and their families/ support systems.

- Honors the person's wishes concerning life closure.

23. When a person served dies, opportunities are provided to other persons in the program, family/support systems, and personnel to:

- a. Express grief and remembrance.
- b. Develop and participate in:
 - (1) Memorial services.
 - (2) Memorial rituals.
 - (3) Other forms of grief expression.

Examples

A program invites personnel and persons served to pay their last respects to each person served after he/she passes away and before the body is removed from the room.

The persons served life may be remembered at a memorial service open to all personnel, persons served, and community members.

Personnel have opportunities to attend a community service for a person served with whom they had a close relationship.

Leadership contacts personnel who had a particularly close relationship with a person served to inform him/her of the death before he/she comes to work.

- Memorial rituals?

- Other forms of grief expression?

Survey Preparation Questions

- 23.** Explain what happens when a person served dies. How are persons served, family/support system, and personnel provided opportunities to:

- Express grief and remembrance?

- Develop and participate in:

- Memorial services?

NOTE: CARF thanks the Alzheimer's Association for permission to include information from the publications titled *Dementia Care Practice Recommendations for Assisted Living Residents and Nursing Homes —Phase 1 and Key Elements of Dementia Care in the examples and survey preparation questions that accompany the Dementia Care standards.*

