Nurses’ Guide to BPSD

Behavioral and Psychological Symptoms of Dementia

BPSD
This publication is intended for the use of physicians and other professionals involved in the study and management of BPSD, and is not intended for use by patients and their caregivers. The International Psychogeriatric Association assumes no responsibility or liability in connection with the information and recommendations provided herein.

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Nurses' Guide to BPSD
The International Psychogeriatric Association's Nurses' Guide to BPSD is a specialized guide to support the needs of the nursing, scientific and professional communities who care for the elderly with dementia. The Nurses' Guide to BPSD has been made possible through the efforts of several nurse researchers and scientists. We gratefully acknowledge the work of the authors, contributors, reviewers, and editors.

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BPSD Resource Materials
The BPSD Educational Pack is a compilation of seven modules that present a useful overview of the presentation and causes of BPSD, constructive guidance on pharmacological and non-pharmacological treatment interventions, and information on caregiver education and support. Each module concludes with a reference and recommended reading list. The content of the BPSD Education Pack is designed to contribute to the improved management of dementia patients with BPSD and reduce some of the stresses experienced by caregivers and families of dementia patients.

About IPA
The mission of the International Psychogeriatric Association (IPA) is to improve the mental health of older people everywhere through education, research, professional development, advocacy, health promotion, and service development. IPA provides physicians, healthcare professionals, and scientists with information about behavioral and biological aspects of mental health in the elderly, through publications, meetings, and special educational projects. IPA keeps professionals aware of current news and international perspectives on research, clinical practice, innovative developments, and significant literature in the field. IPA works actively to promote research in the field and to facilitate international consensus and understanding in psychogeriatric issues.

With grateful appreciation, the International Psychogeriatric Association (IPA) acknowledges the support received from

ACKNOWLEDGMENTS
Janssen-Cilag and Organon for the development and design of these educational materials.

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From a clinical point of view, another useful way to classify these symptoms is in terms of analogous psychiatric syndromes; e.g., delusions, hallucinations, and paranoia can be viewed as psychotic symptoms while depressed mood, apathy and amotivation can be considered depressive symptoms. Similarly psychomotor agitation may be considered a symptom of anxiety or depression. Such considerations may be useful in choosing among approaches for intervention.

Behavioral and psychological symptoms characterize dementia with cognitive deficits due to neurological degeneration. They are known clinically as BPSD. Although formal research in BPSD is limited, their common association with dementia has long been recognized. All primary care staff involved in the management of patients with dementia should be familiar with the range of BPSD and their treatment. (An overview may be found in the Primary Care Physicians Guide to BPSD pages 9 - 11.) A list of common BPSD is shown in the Table below:

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<th>Behavioral and Psychological Symptoms of Dementia (BPSD)</th>
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Behavioral and psychological symptoms of dementia (BPSD) are very common (up to 90% of people with dementia will experience some behavioral or psychological symptom during the course of their dementia). BPSD cause significant distress to patients, their families and caregivers if not effectively managed.

Interventions for BPSD are equally or more effective than those for cognitive symptoms of dementia.

All nurses involved in “front-line” care of patients with dementia should be familiar with clinical manifestations and management of BPSD.

Non-pharmacological interventions should be considered for all severities of BPSD.

A variety of conceptual models and approaches guide nurses’ interventions and practice. The approaches and models identified in the literature and discussed here are the Person Centered Approach (PCA), the Validation Approach, the Need-driven Dementia-compromised Behavior Model (NDB), and the Progressively Lowered Stress Threshold Model (PLST).

Medical, nursing, and psychosocial interventions that are tailored to an individual person’s needs and abilities are the most effective.

Nurses have an important role in supporting the family at home during early to moderate stages of dementia, and in residential care settings during its severe phases.

Nurses can benefit from support in their patient care role. This can be provided through support with individualized patient care planning and clinical supervision.

BPSD can often be prevented and successfully treated.

Management of BPSD requires understanding of the complex interplay of pathological, psychological, interpersonal, social and environmental factors.
On an interactive level, behavioral and psychological symptoms of dementia (BPSD) can be seen as attempts to communicate. The way we see patients with dementia is crucial for the way we meet and interact with them. When a person with dementia says or does something that we don't understand there is a risk that we see the behaviors as being without meaning. We could even explain the “meaningless” as being a part of the disease and the confusion. This may lead to a risk that we, in turn, view the patients and their world as being without purpose and meaning. Several authors have emphasized the importance of seeing the person behind the diagnosis of dementia. For nurses, it is further important to understand the perspective of the person with dementia, and by doing so, seek to understand a behavior as a form of communication. Patients with dementia have, as a result of the disease, difficulties communicating their wishes and needs. One great challenge for nurses is to interpret the patient’s cues. Behavior could be one, very important cue.

The term behavioral problems reflects the problem that others have interpreting the meaning rather than the individual’s experience. However, several other terms are used in the literature—disturbing behaviors, disruptive behaviors and, more recently, challenging behaviors. The term BPSD will be used in this Nurses’ Guide to reflect that the behaviors are connected to difficulties created by dementia. There is no global intervention or easy “to do” list for managing different types of behaviors or symptoms, nor should there be. The main goal for nurses is instead to try to interpret and understand the behavior and adapt interventions individually to each person’s needs. The goal for this guide is to provide some ideas of how to structure nursing care for the benefit of the patient with dementia. Providing compassionate, culturally sensitive and evidence-based care to people with dementia is not easy, and nurses also need support. This guide will set forth ideas about how to support nurses in order to strengthen their relationship with patients and families.

This guide will focus on five main questions:
1. What is the prevalence of, and which conditions seem to be correlated to, different behaviors?
2. Which conceptual models and approaches are presented in the literature?
3. Which nursing interventions have been shown to be effective in relation to different behaviors?
4. How can nurses support patients with dementia and their families?
5. How can the nurses be supported in their role?
Reports of the prevalence of BPSD show a great variability. Some studies have been focused on the prevalence of specific behaviors such as screaming, verbal aggression and physical aggression, while others have focused on behavioral problems or disturbances. Prevalence is measured in different contexts; for example, patients being cared for at home, in institutions, or at different stages of the disease process. Eastley and Wilcock found that 52% of patients with Alzheimer’s disease in non-institutional settings exhibited some aggressive behavior. Reisberg et al. found that 58% of outpatients with Alzheimer’s disease had behavior symptomatology, most commonly delusions and agitation. Studies of patients in long-term care settings have shown the prevalence of BPSD as high as 95% with higher rates noted with greater dementia severity. Behavioral symptoms tend to worsen with disease progression and are strong predictors of institutionalization. Although prevalence rates vary, BPSD occur more frequently among nursing home residents. This is in line with studies by Hwang et al. and Beck et al. showing that severe cognitive impairment was positively associated with BPSD. Other correlates to aggressive and screaming behavior are poor ability to communicate, poor quality of social interaction and physical dependence. Some studies have also shown patients’ pre-morbid personalities correlate with BPSD while others have not. Several symptoms also are interrelated. For example, the presence of hallucinations and delusions are related to screaming and aggressive behavior.

The presence of BPSD creates other difficulties. BPSD are correlated with an increased rate of falls, delayed onset of sleep, and disruption of nighttime sleep. In addition, BPSD have been reported as a major stressor to nursing staff who care for persons with dementia. The picture of BPSD is very complex and there are no easy answers. Several factors are interrelated, such as the environment, the disease, and the nurses’ influence. Once again, we need to focus on the individual with dementia. Recent research documents that across care settings and stages of disease, apathy and agitation are common phenomena and that the predominates behavior fluctuates throughout the day.
Nurses use a variety of conceptual models or theories on which they base their understanding of behavioral and psychological symptoms associated with dementia. These models can guide research-based interventions and practice. Models identified in the literature include the Person Centered Approach (PCA), the Validation Approach, the Need-driven Dementia-compromised Behavior Model (NDB), and the Progressively Lowered Stress Threshold Model (PLST). Some of the models were derived from theory and others from practice. The empirical evidence varies. This has to be taken into consideration when reading this section. The models are summarized below.

**THE PERSON-CENTERED APPROACH (PCA)**

The person-centered approach was developed in the United Kingdom by Tom Kitwood and the Bradford Dementia Group.\(^2,32\) It teaches an understanding of the person and the behavior that the person is engaged in, rather than management of the behavior. The approach involves asking questions that pertain to the person's behavior like, "What does this tell us about the way in which the person is interpreting events or stimuli?" It requires nurses to look behind the behavior presented by the person to seek an understanding of what the behavior is communicating.\(^2\) Kitwood and Bredin\(^33\) further propose that there are four global subjective states related to well-being and maintained personhood:

1) A sense of personal worth (i.e., being valuable to others)
2) A sense of agency (i.e., being able to make things happen in the world)
3) Social confidence (i.e., reaching out to others and knowing that there will be a positive response)
4) Hope (a kind of intuitive, basic trust that enables the person to feel that whatever happens, they will still be safe and well)

Failure to provide care that supports well-being is designated by Kitwood\(^34\) as a "malignant social psychology" which undermines the ability to maintain personhood, in turn leading to emotional stress and increased behavioral "disturbances." In order to evaluate the care provided, an observational tool, Dementia Care Mapping (DCM), has been designed.\(^35,36\) The method is used in the UK and internationally.\(^37\) DCM methodology is well-documented and seeks to evaluate care from the patient's perspective. The effectiveness of the method as well as the approach have been reviewed by Adams\(^38\) and Beavis et al.\(^39\) suggesting that the face validity and reliability of the method are good, but other aspects of validity can only be regarded as moderate. Beavis and colleagues\(^39\) conclude that the theoretical background of DCM appeals to nurses wishing to improve the quality of care. However, the method is time-consuming and requires considerable training and nursing resources. Thus, there is a need for further investigation in order to evaluate DCM as a tool of nursing care.\(^39\)

**THE VALIDATION APPROACH**

Validation Therapy or the Validation Approach\(^40\) emphasizes the need to respond to hidden feelings and meanings behind the person's speech and behavior. The Validation Approach also seeks to understand the "internal context" in which the behavior is taking place and to make sense of it, (i.e., to assume that a person's words and actions have a real sense of purpose and value).\(^41\)
The therapy emanates from the "here and now" of the person's experience, which may, of course, differ completely in time and orientation from our own understanding of reality. The approach further emphasizes the importance of respect for the world and feelings of the person with dementia, and the validation of those feelings. However, the effectiveness of this therapy remains open to question. Keady points out that since Validation Therapy focuses on the individual and his or her need to be valued, the approach is as robust as any other communication-based intervention in dementia care.

NEED-DRIVEN DEMENTIA-COMPROMISED BEHAVIORAL (NDB) MODEL

The NDB model offers a view of BPSD as expressions of unmet needs or goals for the person with dementia, and provides a conceptual framework for different behaviors as an attempt to convey some meaning. These unmet needs may be emotional, social, physical or psychological in nature, but because persons with dementia may have lost language skills necessary to communicate their needs, they do so behaviorally. Factors affecting the need-driven, dementia-compromised behaviors could be background factors which may be neurological, cognitive, general health and psychosocial. Proximal factors are more fluid aspects of the physical and social environment and the changing needs and states within the person.

According to the model, behaviors like wandering, vocalization and physical aggression arise from the interaction between individual characteristics (such as memory, language skills, affective state, gender, and history) and constantly changing environmental or contextual factors (e.g., fluctuations in setting, lighting, or noise levels) that may be stressful or discomforting to persons with dementia. As with most successful models of care, positive outcomes depend on accurate and thorough assessment data, including background and proximal factors that drive individualized interventions.

Family can play a key role in helping staff to "make sense" of verbal and non-verbal communications or behaviors, and can assist nurses to understand long-standing habits or patterns. The model stresses the importance of ruling out physical problems as the cause of behavioral changes. The model presents methods and means for practice interventions. Examples can be found in Beattie and Algase, Kolanowski et al, and Colling and Buettner. Outcomes of care based on the NDB Model are under investigation.

PROGRESSIVELY LOWERED STRESS THRESHOLD MODEL (PLST)

The Progressively Lowered Stress Threshold Model, developed by Hall and Buckwalter, provides a conceptual foundation for the effects of stress on persons with dementia. It serves as a framework for the planning and delivery of care and family caregiver training. According to this model, the cerebral pathology is correlated with a progressive decline in the patient's ability to tolerate stress. Assessment over a 24-hour period usually reveals that most persons with dementia experience a relatively low level of stress in the early morning. Without intervention, stressors begin to accumulate throughout the day until by early afternoon the stress threshold is exceeded, resulting in BPSD (i.e., agitation). According to the model, behaviors may be used as a barometer to determine the patient's tolerance to internal (i.e., hunger, pain) and environmental stimuli (i.e., noise, large crowds). Case profiles illustrating factors identified in the PLST model that may contribute to stress and cause agitation were developed from research findings. As anxious behavior is exhibited, nursing interventions should include...
modifying and simplifying activities and environmental stimuli, to reduce both internal and external stressors. The model predicts that a reduction in stress will diminish anxious behavior and may prevent the onset of BPSD. Interventions for agitated behaviors are most effective when implemented prior to the patient’s peak levels of agitation. However, stimuli should not be reduced to the point of sensory deprivation.

Principles of the PLST model have been used and tested in a variety of settings including home care, long-term care facilities, and acute care facilities.
The primary focus for nursing care and planning interventions is the reason behind the behavior. The recent literature is unambiguous in its conclusions; interventions must be individually tailored to the person and based on the individual's needs and abilities. The results are in line with the NDB Model described earlier, which highlights the importance of a broad knowledge of the patient's present and past situation. Opie et al. further emphasize the importance of multidisciplinary teams and conclude that a combination of individually tailored medical, nursing, and psychosocial interventions is preferred. Nursing interventions consequently must be seen as one highly important part of the patient's care.

PHYSICAL REASONS
It is important to note that BPSD may result from a variety of underlying physical problems. For example, pain or discomfort may elicit agitation. Pain can be difficult to assess in persons with reduced ability to communicate. Studies conducted in acute care and nursing homes show that persons with dementia have fewer analgesics prescribed than persons who are cognitively intact. Thorough assessments and observations of the patient are essential. In recent years a number of pain assessment tools and approaches for use with older persons who are cognitively intact as well as cognitively impaired, have been published in evidence-based protocols and as medical guidelines. Nurses may now choose from a variety of assessment tools including verbal description scales, pain thermometer, and faces pain scales to better detect and manage pain in persons with dementia. These include, for example, the Assessment of Discomfort in Dementia Protocol, Abbey Pain Scale, Checklist of Nonverbal Pain Indicators and the Pain Assessment in Advanced Dementia Scale. Several studies have explored the signs of pain/discomfort observed by nurses.

In summary, nurses observe:
- Facial expressions: Slight frown: sad, frightened face, grimacing, wrinkled forehead, closed or tightened eyes, any distorted expressions, rapid blinking.
- Verbalizations, vocalizations: Sighing, moaning, groaning, grunting, chanting, calling out, noisy breathing, asking for help.
- Body movements: Rigid, tense body posture, guarding, fidgeting, increased pacing, rocking, restricted movement, gait or mobility changes.
- Changes in interpersonal interactions: Aggressive, combative, resisting care, decreased social interactions, socially inappropriate, disruptive, withdrawn, verbally abusive.
- Changes in activity patterns or routines: Refusing food, appetite change, increase in rest periods or sleep, changes in rest patterns, sudden cessation of common routines, increased wandering.
- Mental status changes: Crying or tears, increased confusion, irritability, or distress.
- Medication use: Especially psychoactive drugs that can interfere or interact with analgesics and elicit "unusual" pain behaviors as noted by family carers.

While nurses have a central role in detecting pain or discomfort; their characteristics, attitudes and knowledge can influence the likelihood of detecting pain.

Case Study
A woman, 80 years old with vascular dementia is living in a nursing home. Staff, other patients and visitors see her as being "disturbing" because of repeated periods of screaming. She is also sometimes aggressive towards the staff. The problem is repeatedly discussed with the physician, who prescribes different sedatives without any effect on the behavior. She has lost most of her ability to communicate and has impaired motor and cognitive functioning. Systematic
observations show that she screams mostly when the nurses help her with personal hygiene and at mealtimes.

She often refuses to eat and turns her head away. She is mostly lying or sitting huddled up. The screams are described as being unarticulated, heart-wrenching or groaning and one can sometimes hear the word “ow!” When the woman suddenly dies, her medical record is reviewed. It is discovered that five years ago, her ovaries were surgically removed due to cancer. Postmortem examination reveals widespread metastases. At the time of her death she had no prescribed analgesics.

Comment: This is a real case that was reported to the Swedish National Board of Health and Welfare. The woman was labeled as being “disturbing” by the nurses and even though systematic observations were made, the nurses did not recognize the signs of pain.

THE ENVIRONMENT

As persons with dementia have difficulties adapting to their environment, the environment has to be adapted to them. The literature is consistent when it comes to the environment as an etiological factor in BPSD, but is not consistent when describing adaptation of the environment as an intervention. Hall and Buckwalter clearly identify that inappropriate levels of stimuli serve as stressors in three ways: over stimulation, under stimulation, and misleading stimuli. Therefore, environmental stimuli should be individually modified to compensate for the person’s lowered stress threshold. Behaviors can be used as a barometer to determine the person’s degree of tolerance. Svensson explains this in terms of Lawton and Simon’s environmental press theory. The less capacity an individual possesses, the more vulnerable s/he is to changes in the environment, conversely the more competent s/he is, the less vulnerable s/he is to changes in the environment. There needs to be a balance between environmental demands and the person’s resources. That is, stimuli must be adjusted to the patient’s changing abilities and needs.

Environmental modifications

The importance of the environment is seen with wandering behavior. Wandering or restless behavior can indicate goal-driven behavior, for example, the patient is looking for someone or wants to go home or to work. Hope and Fairburn developed useful descriptive typology of wandering in dementia that includes nine types such as checking, trailing, excessive activity and night time walking. In such cases validation or distraction might be useful methods. Successful strategies used to deter wandering include environmental modifications, technology and safety, physical, psychosocial interventions, caregiving support and education. Environmental modifications can include camouflaging exit areas by painting the door and wall the same color, or covering the door with drapery. Other approaches used with mixed results include posting stop signs or painting a dark stripe or attaching a piece of duct tape to the floor in front of areas that are “off limits”. Proper identification of bathroom areas, e.g., with a large picture of a toilet, and the resident’s room, with their name and a personal picture, can help reduce wandering in persons who frequently get lost. Nurses can use the Algase Wandering Scale to determine the degree of wandering behavior and the success of interventions for wandering. Persons who are at risk for going out and not finding their way home may wear a bracelet-like tracking device that allows caregivers to monitor their movements. A variety of aids have been developed in different countries. In the United States, for example, the Alzheimer’s Association Safe Return Program registers
persons with dementia and alerts law enforcement officials when someone has wandered off, and needs to be found, or is returned to their home or facility.

The importance of light has been described by Satlin et al.90 who documented that evening bright light pulses decreased sleep/wake cycle disturbances. Eighty percent of the persons exposed to this treatment, especially those that experienced sundowning, improved. In another study that manipulated lighting, Frengley and Mion 91 used low lighting in combination with music and eating interventions, to increase food consumption, decrease noise levels, and improve staff response. More recently, Mishima and colleagues92 documented that sleep and behavior problems improved with a four-week light therapy treatment.

Research on the use of white noise (i.e., low intensity, slow rhythmic and monotonous sounds) shows that it produces modest results. When white noise was used to decrease nocturnal wandering, two of eight (25%) of patients improved.93 Similarly, when individualized white noise audiotapes were employed for the treatment of verbal agitation in nursing home patients with severe dementia, 23% had reduced verbal agitation.94 This improvement was achieved despite the fact that treatment monitoring data revealed the audiotapes were only used during 51% of the observations.

The nurse–patient relationship
Nurses are one of the most important factors in the patients' environment, as patients must rely on nurses' care for their daily living. There are two important aspects to care, i.e., the task to be performed and the way the task is performed. Jecker and Self95 describe this in terms of caring for and caring about the patient. Findings from Hallberg et al.96,97 Armstrong–Esther et al.,98 Coulson99 and others, suggest that nurse–patient interactions are focused mainly on the task to be performed, while the relational aspect, to acknowledge the person, is less present. Data from Edberg et al.100 demonstrated that the nurses' communication style could affect the patients' vocal activity. For instance, a harsh tone of voice was related to increasing verbally disruptive behavior; while a soft tone of voice was related to less verbally disruptive behavior. It seems important, then, to highlight not only what to do, but the manner in which it is done.

Communication in the nurse–patient relationship consists of both verbal and non-verbal cues. Although patients with dementia have a decreased ability to communicate verbally due to perceptual, language and memory deficits, they retain an ability to communicate emotions non-verbally, even in the most severe stages of dementia.101,102 However, much is left to the nurse's ability to interpret the patient's cues.103 Several researchers have found that non-verbal communication such as touch, eye contact and, as earlier mentioned, tone of voice is even more important than the spoken word when communicating with patients with dementia.
Guidelines for communication

- Use a calm, reassuring tone of voice.
- State sentences in a positive manner and avoid the use of commands including the word "don't".
- Provide opportunities for the patient to experience a sense of control.  
- Provide consistency in the daily routine and offering simple choices of foods and clothing whenever possible.
- Provide reassurance as necessary; this is usually most effective from a family member or a health care provider with whom the patient is familiar and whose role is established.
- Explain in simple terms what you are going to do prior to moving into the patient's personal space to implement care.
- If the patient can communicate verbally, determine which sense dominates the patient's perception of the world (visual, auditory, kinesthetic, olfactory, or gustatory) by listening to their descriptive words then, communicate with the patient through his or her preferred sense; this promotes a feeling of trust in the patient.
- Use a non-threatening posture, position yourself at eye level with the patient and establish eye contact (unless culturally contraindicated).
- Do not "sneak up" on the patient or approach the patient from behind without announcing yourself.
- The use of touch while providing care should be conducted in a respectful, careful, and unhurried manner. Feil found that gently stroking the patient from the ear lobe to the chin may stimulate the memory of a loved one, such as mother or spouse, and has a calming effect on the patient.

Other communication guidelines:

- Identify yourself and address the patient by name.
- Use short words and simple sentences.
- Ask one question at a time.
- Avoid asking questions that begin with "why", as this often requires a response that patients are unable to provide.
- Give adequate time for response due to the patient's slow information processing.
- Repeat questions or directions when necessary.
- Use nouns (chair, bathroom) instead of pronouns (it, there).
- Speak slowly and enunciate clearly.
- Accompany speech with clarifying or reinforcing gestures.
- Share successful strategies with other staff and family members.

Another important factor in communication is to compensate for sensory impairment as it may result in a misinterpretation of environmental stimuli leading to BPSD. More specifically, studies have shown that impaired vision is significantly related to verbally agitated behaviors and impaired hearing has been identified as a possible cause of agitation. It is therefore important to compensate for sensory deficits by providing devices such as eye glasses and hearing aids. Further, it is essential that glasses with the correct prescription are kept clean, hearing aid batteries fresh, and the lighting adequate, to reduce the potential adverse effects of sensory impairment. Appropriate communication techniques can also help compensate for uncorrected hearing or visual impairment.
INTERVENTIONS IN RELATION TO
ACTIVITIES OF DAILY LIVING
As noted earlier, the implementation of daily care should focus on the "person, and not just the task". In addition, care should be adjusted to meet individual patient needs rather than forcing patients into a routine that is simply convenient for the formal or informal caregiver. Caregivers are encouraged to "listen" and "follow the lead" of the person with dementia. Care provided with this method will ultimately be more effective in meeting individual needs and less stressful to the caregiver.107

Bathing
Bathing is an activity that often creates anxiety for the patients and increases the risk of catastrophic reactions due to a high level of stress.108 The following guidelines109, 110 can reduce the patients' level of stress and anxiety during bathing and increase their safety:
• Ensure that the room is kept at an appropriate temperature. Keep the patient warm and covered as much as possible. Refill the tub with warm water as necessary throughout the bath period so it is consistently warm.
• Make the bathing area as home-like as possible.
• Explain the procedure one step at a time. Give the patient a washcloth to hold and encourage participation in bathing.
• If possible, try to maintain established habits. For example, a person who took tub baths throughout his/her life may find a shower too confusing and frightening.
• If the person is used to taking a shower, a hand-held shower head may provide a greater sense of control and consequently may be less frightening.
• Water temperature should be adjusted so that it is pleasant and the thermostat should be adjusted so that it is not possible for patients to scald themselves. Help the patient to feel the water before entering the tub to assure that it is not too hot.
• Safety items should be installed to decrease the risk of falls: non-skid strips on the floor of the tub, grab bars for getting in and out of the tub, a bath seat to allow individuals to sit above the water if they prefer a greater sense of security.
• It is important to note that the presence of a person of the opposite sex can be distressing for the patient, for cultural, religious or emotional reasons.
• If the patient has arthritis or other medical conditions that impede entry into and out of the tub or shower stall, or cause pain, a mild analgesic 1/2 hour before the procedure may help.

Dining
Eating is essential to maintain adequate levels of nutrition. The dining room environment is very important. If it is too stressful, noisy, crowded or chaotic, there is a risk that the patient will be stressed and react with aggression. Goddaer and Abraham111 hypothesized that "relaxation" music would buffer the general noise level found in dining rooms in long-term care settings and that the music would exert a calming effect that would reduce the frequency of agitated behaviors. Findings revealed significant reductions in the overall level of agitated behaviors (63.4%) as well as physically non-aggressive behaviors (56.3%) and verbally agitated behaviors (74.5%) in the 29 patients studied. These results were confirmed by Denney.112 In addition, Ragneskog and colleagues113 evaluated the effects of music
during mealtime. They reported increased food intake, particularly significant for dessert, and a reduction in irritability, fear, panic and depressed mood. It is important to note that the music should be low and calming.

Meals are complex situations, and besides the environment there are several other factors that could be stressful for the patient. The inability to identify a fork, knife, or the food itself (i.e., visual agnosia), can create anxiety as can problems connected to dysphagia. A thorough mapping of the dining experience as a whole, taking both environmental as well as individual aspects into consideration, is essential.

Finding the toilet
Incontinence and/or voiding in inappropriate places may result from the person’s inability to find the toilet. To compensate, a list of simple measures can be implemented:107
- Create opportunities for the person to find the way to the toilet, (e.g., clear pathways; leave the bathroom door open to make the toilet visible).
- Provide cues to find the toilet, (e.g., signs with pictures as well as words). Ensure that if the person has limited mobility, she or he is seated close to the toilet.
- Use color contrast to help the person with dementia see the toilet. For example, the person may have difficulty seeing a white toilet against white walls and light colored floor. A brightly colored toilet seat will make it easier for the person to see and identify the toilet.
- Adapt the room to avoid the “mirror sign” so that the patient isn’t frightened or distracted from task by his/her own reflection. Cover or remove mirrors as needed.

Rest
The balance between rest and activity is essential and it is important to arrange for short regular rest periods during mid-morning and mid-afternoon.48 Some authors conclude that it is preferable for the person to take a nap or rest in a reclining chair since laying in bed may cause the person to become confused on waking, thinking it is morning and the beginning of a new day.106 For patients with sleeping problems, more daytime activity can improve sleep at night. Ensure that the room is at an appropriate temperature and that the noise level is reduced to a minimum.

Activity
For persons with dementia, as for others, activity has to be meaningful. In this section two types of activity will be presented, Reminiscence and "Simple Pleasures." The importance of everyday activities such as outdoor walks, however, should not be neglected.

Reminiscence is a memory activity that employs purposive and spontaneous remembrances of thoughts, feelings and events.114
The advantages for persons with dementia are that it focuses on remote memory so that short-term memory becomes less important. Reminiscence therapy has been used in interventions with elderly since the mid-1960s but studies involving persons with dementia are still sparse.\textsuperscript{115}

Kovach\textsuperscript{116} describes two selective processes that occur with reminiscence. The individual may choose certain events over others to reminisce about. Kovach\textsuperscript{116} suggests that the content of reminiscence is a representation of the cognitive processes that construct and reconstruct self-knowledge. This has implications for the use of reminiscence as an intervention since the facilitator has to use different cues to stimulate reminiscence activity.\textsuperscript{117} For example, one cue could be a photo album. Retz\textsuperscript{118} concluded that reminiscence could provide a framework for supportive interventions, but emphasizes the importance of further research.

Buettner\textsuperscript{119} developed the "Simple Pleasures" intervention, a multilevel sensorimotor intervention for nursing home residents with dementia. It consists of 30 handmade items, of which 23 are therapeutically valuable and acceptable for nursing home use. Family visits, use of recreational items, and satisfaction with visits significantly improved as a result of this intervention. "Simple Pleasures" has been used in combination with the Need-driven Dementia-compromised Behavioral (NDB) model.\textsuperscript{47,120} The intervention included staff, family and visitors who were introduced to the pleasure items. The results showed that visits from family members increased during the intervention period and they became more satisfied with their visits. The residents became less inactive and more involved with other residents. A significant drop in agitation was seen. "Simple Pleasures" help family members, volunteers and nurses develop meaningful activities together with the person with dementia. Buettner and Fitzsimmons have published dementia practice guidelines for recreation therapy that are excellent for interdisciplinary interventions.\textsuperscript{121}

**INTERVENTIONS AND THERAPIES FOCUSED ON THE PERSON’S SENSES**

Individual sensory therapies, such as aromatherapy, music and therapeutic use of touch can be used as a means to increase relaxation and well-being, but also as a form of activity. For example, an activity that elicits pleasant memories may be calming when a patient is anxious. The process may be enhanced by stimulation of multiple senses (vision, smell, taste, touch, and hearing). Sensory cues may also include looking at photo albums, discussing personal memories, providing a favorite food item, playing a musical instrument or listening to music.

**Snoezelen**

The word is a contraction of the Dutch words for "sniffing" and "dozing". It describes the combination of aroma and relaxation therapy used. Snoezelen was developed in the Netherlands in the late 1980s.\textsuperscript{122,123} It soon gained a significant following in Europe, and later in the United States and Canada.\textsuperscript{124} The concept of Snoezelen is based on the assumption that the world in which we live is a mixture of light, smells, sounds, tastes and tactile sensations that we access through our sensory organs: eyes, ears, nose, mouth and skin.\textsuperscript{122} The aim is to facilitate relaxation for persons with sensory, physical and learning disabilities. It employs various types of equipment to stimulate the senses. A multisensory environment is created through the use of a breeze machine, fiber optic lights, columns of bubble tubes that change colors, soft images projected on the walls, an oil
burner for aromatics, and gentle music to enhance feelings of relaxation. The Snoezelen approach has been adapted to elder care in several countries but, evidence of its efficacy remains limited. Moffat et al. showed an increase in ratings for happiness, interest, and the number of subjects that remained calm throughout the sessions. Dowling et al. and Baker et al. extended the work of Moffat et al., and investigated the effects for persons with dementia. A decrease in "socially disruptive behaviors" was seen after repeated sessions. The effect of Snoezelen for persons with BPSD is however primarily anecdotal, even if a majority of the articles indicate positive outcomes.

Music
As noted earlier, soothing music at dinner time can reduce irritability and agitation for patients with dementia. Individualized music has also been used as an alternative intervention for the management of agitation. Gerdner theorized that the presentation of carefully selected music, based on personal preference, can provide an opportunity to stimulate remote memory. This changes the focus of attention and provides an interpretable stimulus, overriding stimuli in the environment that may be confusing for the patient. Eliciting memories associated with positive feelings (happiness, love, etc.) may have a soothing effect, which in turn can prevent or alleviate agitation. A correlation is posited between the degree of significance music had in the person’s life before the onset of cognitive impairment and the effectiveness of the intervention. To test this theory, Gerdner compared the immediate and subsequent effects of individualized music and classical “relaxation” music on the frequency of agitated behaviors in 39 elderly persons with dementia. The selection of individualized music was based on information obtained from a close family member. There was a significantly greater reduction in agitation during and following individualized music, compared to classical music. The intervention is relatively inexpensive and requires minimal time expenditure. Subsequent research also supports the effectiveness of individualized music in the management of agitation when implemented by trained staff and family members.

Touch
The importance of touch is well-documented. Different types of massage have been used alone or in combination with other techniques to increase relaxation. Sansone and Schmitt evaluated the effects of gentle massage on two groups of elderly nursing home residents: 1) those suffering from chronic pain; and, 2) those with dementia who were exhibiting anxious or agitated behaviors. The results showed that pain scores declined in the first group and anxiety scores declined in the second. Most nurses (84%) reported that the residents enjoyed receiving tender touch, and 71% thought that the massage improved their ability to communicate with the residents. Kilstoff and Chenoweth showed similar results from a day care center when introducing gentle hand treatment with essential oils. Findings indicate improvements for clients including increased alertness, better sleep at night, less agitation, withdrawal and wandering, strengthening of the relationship between family carer and the patient, and an improvement in feelings of health and well being for both. Family carers also reported less distress, improved sleeping patterns and feelings of calm. They found the treatment useful in helping them manage the difficult behaviors exhibited by their relative with dementia.
Researchers have evaluated massage, in combination with other methods. Remington used calming music, hand massage, or the combination of both to reduce agitated behavior for patients in a nursing home. Subjects receiving either intervention alone or in combination exhibited significantly less agitation than the control group up to one hour following the intervention.

Smallwood et al. reported more positive effects on motor behavior with a combination of aromatherapy and massage as compared to conversation and aromatherapy or massage only. By contrast, Brooker et al. found significant improvement in behavior in only one of four patients using the combination of aromatherapy and massage, even if the nurse’s opinion was that all patients benefited from the intervention.

Aromatherapy
Aromatherapy is based on the notion that aromas have positive effects on mood, sleep and stress. The response to aromas will differ depending on the person’s background and experiences. Certain aromas may be associated with certain experiences or life-periods and trigger positive or negative responses. Aromas commonly used in the therapy are lavender oil, lemon balm, jasmine, tea-tree oil and orange. It is important that essential oils are derived from the concentrated essence of the plant e.g., the root, seed, trunk, leaf, fruit, or flower. The effects of oils are said to be dependent on its characteristics. The aroma can be administered by a cotton ball, and it is important that essential oils are not applied directly on to the skin or used internally because they could cause irritation.

The use of aromatherapy in relation to BPSD has grown in popularity over recent years and is (or has been) accompanied by a growing amount of empirical research. Among the studies, reported that lemon balm oils and lavender increased functional ability and decreased difficult behaviors. Wolfe argued that lavender had a positive impact on relaxation. But Gray and Clair found no significant benefits in a small sample of 13 older persons with dementia who were regarded as “resistant to medication”.

Although there is now empirical evidence for efficacy of aromatherapy and no harmful effects have been identified, more research is warranted to refine use.

Art
Art may be used “as a small window to the inner world” of the person when the disease makes language difficult or impossible. Creative art activities also offer the opportunity for an increased sense of mastery. The person can achieve a sense of control by manipulating art materials and making decisions within a limited sphere. In addition, sensory stimulation is provided through the exploration of various art medium, color, and form. Art also provides a means for the person to “unveil” his or her personal identity through the recreation of personal history. This is closely linked to the role of art in reminiscence. Sanzotta developed a three-dimensional interactive art form specifically designed for persons with dementia, using visual, tactile and olfactory stimulation. Tactile stimulation is provided by incorporating removable items (i.e., pot holder, leather baseball glove) or sculpted objects into the art work and olfactory
stimulation is provided by adding aromatic oils to the paint. The art is used to depict nostalgic intergenerational activities such as fishing, quilting, gardening, baking cookies or playing baseball. Although there have been no studies to evaluate the effectiveness of three-dimensional art, nursing staff have reported positive patient responses and there is an increased use of this intervention in long-term care settings.

Pets
Recent findings demonstrate that a pet has several positive effects for elderly people in general. A pet such as a cat or dog may limit the psychological impact of social isolation for the elderly. And, pet owners seem to remain relatively healthy emotionally compared with non pet-owners during crisis. Several studies have shown similar findings among persons with dementia. For example, Fritz et al. found that the presence of a pet in the home seemed to reduce agitation and aggressive behaviors. A "therapy dog" in a special care unit increased socialization behaviors for the residents. Similarly, Churchill et al. showed that the presence of a therapy dog enhanced socialization as demonstrated by increased verbalization, smiles, looks, leans and tactile contact. However, there were no significant changes in agitation, possibly because of the low occurrence of agitation at baseline. Reports however are mainly anecdotal and further systematic research is required to demonstrate the benefits of pets and the matching of this form of therapy with patients.

Video Respite™ and Simulated Presence Therapy
Videotape use as a distraction or activity has emerged a resource for both formal and informal caregivers of persons with dementia. Video Respite™ refers to the creation of videotapes used to provide a meaningful activity to capture and maintain the attention of the person thereby creating respite time for the primary caregiver. Video tapes are designed to stimulate remote memory. Generally, there are two methods used to create these tapes: 1) a family member articulates scripts with individualized content or, 2) professional actors or actresses present simple, slow-paced conversations. With either method, topics relate to experiences, people and objects that are likely to be ingrained in long-term memory. Early research findings reveal that most persons with dementia can watch and participate with the videotapes. Staff on special care units reported the tapes were calming for residents. Malone-Beach et al. evaluated the usefulness of video respite in relation to the abilities of persons with dementia. Analyses of the observations of the residents confirmed that participation varied considerably among them and that cognitive status was not a useful guide in predicting levels of participation. Some residents showed no interest in the tapes or television in general, whereas other enjoyed sustained viewing facilitated by the elimination of environmental distractions. Hall and Hare evaluated the effectiveness of one selected video tape ("Remembering When") in the series of ten Video Respite™ tapes. Although findings did not reveal a significant reduction in agitated behaviors, there was a significant increase in positive behaviors.
Simulated presence therapy uses a similar concept, by capturing a personalized conversation on audiotape about personal memories and family anecdotes. Family members are instructed on how to prepare a conversational-style audiotape incorporating soundless spaces, i.e., periods of silence, designed to encourage persons with dementia to respond and engage in the conversation. The person with dementia listens to the tape through headphones when agitated. The concept is intended to decrease agitation and increase social interaction. Woods and Ashley and Camberg et al. showed that using a familiar voice, usually that of a family member, resulted in fewer patient behavior problems as reported by staff, and decreased staff burden.

PHARMACOLOGICAL AND PHYSICAL RESTRAINTS
A continuing discussion about the use of pharmacological and physical restraints is important in the nursing field. As legislation about the use of physical restraints varies greatly between different countries, it will not be discussed in this section. In the literature, the use of pharmacological restraints has shown little or no effect on BPSD, and in some studies restraints have been shown to even exacerbate the behavior. Psychotropic drugs are often prescribed to persons with dementia who exhibit agitation. The use of chemical restraints has to be discussed by the multi-disciplinary team and used with caution since medication could increase confusion and the incidence of falls.

Physical restraints have historically been used to calm patients with agitation or restlessness. However, these measures often trigger rather than reduce the behavior. Studies have shown that nurses who use restraints and those who do not, differ in philosophy and culture as well as the availability and perceived legality of using restraints. In one study, nurses with negative attitudes toward older persons were more positive about the use of restraints. The use of restraints is sometimes justified to prevent injury. Staff education and consultation interventions have been shown to be effective in reducing the use of restraints.
CAREGIVER SUPPORT WHEN CARING FOR A FAMILY MEMBER AT HOME
Nurses have an important role in supporting the family. Family members often care for persons with dementia at home during the early to moderate stages of the disease. 70% of persons with dementia are cared for in their own home.185,186 (see BPSD Module 4—Role of Caregivers). Nurses’ contributions can range from support in the person’s home to nursing in residential or long-term care. In recent years, five different reviews of the effects of psychosocial interventions for carers of people with dementia have been published: Brodaty et al., Schulz et al., Pusey and Richards, Charlesworth, Cooke et al. Pusey and Richards categorized four different types of interventions: technology-based, group-based, individually-based and service configuration. They concluded that individually-based interventions that utilized problem-solving and behavior management demonstrated the best evidence of effectiveness and that future development of interventions should be based on this model. Cooke et al. also found that the combination of social and cognitive support was relatively effective. Schulz et al. were more positive, concluding that caregiving intervention research has demonstrated that services are highly valued by caregivers and can delay institutionalization. Brodaty et al. found an overall significant though modest effect for family caregiver interventions. Successful psychosocial interventions were more likely when patients as well as caregivers were involved, when the extended family was included and when there was a greater “dose” of intervention. They also reported that caregiver interventions could delay nursing home admissions. Mittelman and colleagues were successful in postponing nursing home placement of persons in the early to moderate stages of dementia, though a comprehensive support and counseling program for family caregivers. Similarly, a nurse-coordinated program was effective in delaying residential or long-term care placement. Examples of successful caregiver programs are (i) from Sydney, a comprehensive training program for people with dementia and their caregivers, (ii) from New York, a counseling program for primary caregivers and other family members and (iii) from Manchester, a combination of behavioral and stress reduction techniques. All three programs were tightly structured and were successful in reducing caregiver depression or psychological morbidity. The Sydney and New York studies also demonstrated significant delays in nursing home admission rates.

FAMILY INVOLVEMENT IN CARE
Relocation to a nursing home does not necessarily mean an end to the stress experienced by family caregivers. Following placement, family members have to develop a different caregiving role. For most families this is a new situation when they have to change their role from direct care tasks to a more indirect, supportive, interpersonal role. Thus, they need support from nursing home staff in how to go about making changes in their caregiver role.

To facilitate this transition a Family Involvement in Care (FIC) protocol was developed by Maas and colleagues to diminish potential conflicts, decrease family and staff stress, and increase satisfaction with caregiving roles. The FIC intervention is
a step-by-step method designed to assist the collaboration of nursing home staff and family members by achieving a negotiated partnership, in which control is shared and the particular expertise of each is used to best advantage. The partnership emphasizes cooperation between staff and families and includes specific and clearly outlined roles for the family caregiver in the institutional setting.

Key elements of the FIC protocol include:
1) Orientation of the family to the facility and partnership role;
2) Negotiation and formation of a partnership contract;
3) Education of family members for involvement in care;
4) Follow-up family member and staff evaluation and renegotiations of the partnership contract as needed.

It is important to recognize that the family caregiver has extensive experience and knowledge in the personalized care of their “loved one” and must be viewed as an important resource in nursing care. The family caregiver has a wealth of information regarding the resident’s personal history, individualized routines, and personal preferences. They may be able to share caregiving tips that they have found to be effective through years of trial and error. Family members should thus be an important part of the dementia care team, as working together in a team approach can ease stressors for both the nursing staff and the family. A qualitative study conducted by Duncan and Morgan200 reported that family members felt they were contributing to the quality of care when staff recognized the value of this knowledge and used it to individualize care. Family members perceived this as an important step toward the establishment of a positive family-staff relationship. However, the degree of involvement from the family will vary depending on their desires and abilities.
The way in which nurses view and treat the person with dementia has an impact on the relationship and interaction with them. The nurse can either enable or deny the “self” presented by the person. This in turn has implications for the way that different behaviors are viewed. There is a risk that BPSD are interpreted only from the staff perspective rather than as an expression of unmet need. For example, if a behavior is perceived as a consequence of the individual’s illness there is a better chance that the behavior will be accepted. If, by contrast, the behavior is perceived to be willful or a conscious decision, there is a risk that the resident will be viewed as unappreciative, resistive to help or manipulative. The nurse’s view of the patient and his or her behavior has a direct impact on the provision of nursing care.

Nursing care must take into account the primary and secondary effects of the disease on the patient’s competence, experiences and reactions. Nurses, in turn, have to be supported so as to minimize the risk of a vicious cycle where nurses withdraw from the patients and provide only task-oriented care that may then cause feelings of guilt in the nurse and further withdrawal on the part of the patient. For example, Åkerlund noted that the nurse’s uncertainty about which interventions are “right” or “wrong” can create anxiety. Another study showed that nurses experienced the patients as “being in their hands”, implying an emotional responsibility that could be heavy to bear. There is thus a need for support structures for nurses in dementia care.

There are several interventions aimed at supporting the nurses working in dementia care. Cohen-Mansfield et al. and Goldsmith et al. evaluated staff training programs aimed at reducing patients’ wandering behavior. These interventions had a positive effect on the nurses’ cognitive knowledge of wandering, but no effect was seen on the wandering behavior of patients.

Other interventions have been directed to the provision of care: integrity-promoting care, client-oriented nursing care, supports in the design of interventions, a combination of individualized care and clinical supervision, which had a positive effect on the patients’ behavior. The intervention described by Bråne et al. consisted of staff education about dementia, with an emphasis on symptoms and difficulties that follow the progression of the disease. The education also involved a discussion of patients’ needs for security and integrity, based on Erikson’s theory and on the effect of the environment. The staff then decided how to change care provision and ward milieu and were supported throughout this process. The intervention had positive results compared to a control ward in terms of decreased patient anxiety, confusion and depressed mood. No differences in the patients' emotional states were detected; however, improved activity and sociability as well as clearer verbal cues were noted. Positive effects were also seen during morning care in terms of increased cooperation from the patient and increased verbal contact initiated both by patients and nurses. Only minor changes were noted in staff opinions about their work, perhaps because the interventions were mainly task-focused.
Edberg and Hallberg evaluated the implementation of individually-planned care and clinical supervision on a ward for patients with severe dementia. Intervention was focused on the task aspect (individually planned care) as well as the relationship aspect (clinical supervision) of nursing care. The intervention started with a two-day training session for nurses on both the experimental and control wards. Over the next year, nurses on the experimental ward were supported in adjusting care according to each patient's individual abilities and needs after a thorough assessment was made of the patient's history, cognitive and functional abilities and present needs. Nursing interventions were based on nursing diagnoses that focused on the probable underlying causes of patients' behavior. Systematic group supervision of the experimental ward staff started simultaneously with care planning. Supervision included all staff on duty and focused on one patient at a time. The focus for supervision was; "What do I experience in the encounter with the patient?" and "How do I think that the world looks from the patient’s perspective?"

Intervention had several positive outcomes: the frequency and occurrence of difficult physical and vocal behaviors decreased; patients' functional performance and orientation improved; and nurse-patient cooperation during morning care improved. Further, several positive results were seen for the staff: nurses' creativity and work satisfaction increased while tedium, burnout and strain decreased. A combination of support directed to the provision of nursing care and emotional support thus resulted in several positive effects for patients' behavior, nurses' well-being, and nurse-patient relationships.

Although clinical supervision is frequently highlighted in the literature, empirical knowledge of dementia care is still limited. Considerable work has been conducted in the United Kingdom evaluating clinical supervision in other contexts, for example in mental health nursing. In Scandinavia, several studies have shown positive results for psychiatric nurses and district nurses. In recent years, clinical supervision has been introduced in several countries, thus acknowledging the nurses' need for support.

In Australia, the Health Ministers' Advisory Council recommended that mental health services staff should have access to formal and informal clinical supervision. A survey in the United Kingdom showed that clinical supervision was implemented, in varying degrees, for 92% of all National Service Providers. Even if clinical supervision is given in different ways in different settings, it can be an effective means of supporting nurses in their provision of care. It is important that nurses have the opportunity to reflect on patients as unique persons with lived experiences. Clinical supervision can facilitate this perspective in order to promote high quality in nurses' interactions with the patients.
Behavioral and psychological symptoms of dementia are complex phenomena. The nursing care of persons with BPSD requires that nurses assess for the underlying cause of the patient's behavior. There is no single intervention or solution for BPSD---Interventions must be tailored to address the underlying cause. BPSD can be stressful for family members, staff, caregivers and patients. Nurses have a central role in the planning and provision of nursing care as well as in supporting the family. These responsibilities, in turn, highlight the need for supportive structures for nurses.

**GLOSSARY**

**Agitation (psychomotor agitation)**
Excessive motor activity associated with a feeling of inner tension. The activity is usually nonproductive and repetitious and consists of such behaviour as pacing, fidgeting, wringing of the hands, pulling of clothes, and inability to sit still.

**Apathy**
Lack of passion, emotion or excitement; indifference to appeals to feeling or interest.

**Delusion**
A false belief that cannot be changed by rational argument and is not shared by the person's culture.

**Depressed Mood**
Sadness or loss of pleasure in activities that normally produces pleasure.

**Hallucination**
A sensory perception with no external stimulus.

**Wandering**
Meandering, aimless or repetitive locomotion that exposes the person to harm. Frequently incongruent with boundaries, limits or obstacles.

**Aggression**
Act of hostility that can be verbal or physical.

**Amotivation**
Absence of the internal drive to accomplish tasks.

**Anxiety**
The apprehensive anticipation of future danger or misfortune accompanied by a feeling of dysphoria or somatic symptoms of tension. The focus of anticipated danger may be internal or external.
IPA Educational Programs for BPSD

In keeping with the IPA's mission, the goals of the BPSD educational programs are to:

- Inform health care practitioners and caregivers about BPSD
- Improve understanding and knowledge of the prevalent causes, effects and ways of alleviating and preventing BPSD
- Stimulate research into BPSD and to advance the body of scientific and health practice knowledge about BPSD

Educational modalities include:

- BPSD Educational Pack (2003 Edition)
- Primary Care Physicians' Guide to BPSD
- Nurses' Guide to BPSD
- Journal publications
- Internet website
- BPSD slide kit (available to download)

For more information about IPA educational programs for BPSD, please visit the IPA Website, [http://www.ipa-online.org](http://www.ipa-online.org), or contact:

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For a broader perspective and further clarification of dementia we suggest the following sources:


- For additional information on these IPA resource materials, visit www.ipa-online.org or contact IPA via email at info@ipa-online.org, by telephone: +1.847.501.3310, or fax: +1.847.501.3317.