

# Behavioral and Psychological Symptoms of Dementia (BPSD) Educational Pack



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## MODULE 5: Non-pharmacological management

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## **Key messages**

- Non-pharmacological interventions are usually first-line in dealing with milder behavioral and psychological symptoms of dementia (BPSD). There is a limited, but rapidly growing, body of research supporting the use of these interventions.
- Problems without an environmental trigger that are severely distressing to the caregiver require medication often (though not always) in conjunction with non-pharmacological interventions.
- Symptoms that are most responsive to non-pharmacological interventions (Teri et al., 2000; Teri et al., 1997) include:
  - depression/apathy
  - wandering/pacing
  - repetitive questioning/mannerisms.
- The ideal environment for a patient with dementia is one that is non-stressful, constant and familiar.
- A general approach to behavioral interventions includes:
  - identify the target BPSD
  - gather information on the BPSD
  - identify the triggers or consequential events of a specific symptom
  - set realistic goals and making plans
  - encourage caregivers to reward themselves and others for achieving goals
  - continually evaluate and modify plans.
- Recreational, music, and bright-light therapies are interventions that have been shown to reduce anxiety and agitation in other populations. For patients with dementia, reality orientation and music therapies have the strongest research base (Spector et al., 2000a; Woods, 2002), although a number of recent studies have begun to determine the impact of other recreational therapies.
- Psychological and psychosocial interventions including psychotherapy (individual, group and family), when tailored to the individual needs of patients, families, and caregivers, can have a significant impact on patients' well being (Mittleman, 2000; Teri et al., 2000; Teri et al., 1997). Such interventions need to be modified, as individual needs change during the course of the illness.

## **General principles**

Non-pharmacological interventions should be considered as first-line for some of the milder symptoms of BPSD. This module should be studied with Module 4, as caregivers will implement many of the non-pharmacological interventions described here. Thus, to have a significant impact, interventions must be designed so that they can be easily learned and implemented by family or institutional caregivers.

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- Considering cost-containment efforts and the fact that most dementia patients are managed in the home or long-term care settings, low-technology, inexpensive interventions stand the best chance of broad-based implementation and, therefore, widespread impact.
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There are some general principles that underlie non-pharmacological management. First, prior to the initiation of any intervention, it is critical to rule out and treat any potential medical causes of BPSD. Subsequently, it is necessary to continually modify and adapt solutions to the patient's problems, as programs must be tailored to the individual to be most effective.

Caregivers are an essential part of the care of the person with dementia, but often suffer because of the burden imposed by the dementia (see Module 4). As adaptation is central to the success of non-pharmacological interventions, the caregiver has to cope not only with caring for the person with BPSD, but also with the implementation of new strategies. The degree of stress felt by caregivers can impact on their ability to carry out these recommended changes without additional burden. Most importantly, the dignity of patients and caregivers should be respected at all times and their wishes should be considered throughout management programs.

## ***Environmental interventions***

Environmental interventions are based on the recognition that a person with dementia is no longer able to adapt, and thus, the environment must be adapted to the specific needs of the patient. The ideal environment is non-stressful, constant and familiar (Eimer, 1989). If stressful, the environment can contribute to, or exacerbate, BPSD. On the other hand, a supportive environment can alleviate BPSD. (See Appendix C for summary of approaches that have been trialed).

## **Physical environment**

Wandering is a specific BPSD for which a number of recommendations relating to the physical environment have been suggested. Whether it is from home or a nursing home, wandering poses a threat to the safety of the patient and is a source of significant anxiety for caregivers.

Among provisions to decrease dangerous wandering are:

- accessibility to places for ambulation
  - either indoors or in contained outdoor areas
- digital locks to be used by those cognitively intact
- artificial partitions
- electronic bracelets
- electronic alarm systems.

In more general terms, the following environmental variables are helpful in providing a 'non-stressful' environment in patients with dementia:

- use of soft lighting and calm colors such as tan or peach (including the color of uniforms)
- using carpets to absorb sound
- adding appropriate music
- flowing water, pictures, home like settings
- visual barriers (to prevent exiting).

The following are more likely to be deleterious, confusing or frightening:

- abstract/noisy designs which can be confusing or disturbing
- mirrors (outside dressing areas/bathrooms) which may be confusing
- loud telephone bells or paging systems

- frequent re-design or room changes.

## Temporal environment

It is important that the daily schedule of patients suffering with dementia remains as stable as possible since unfamiliar routines can cause stress and consequently exacerbate BPSD (Orrell and Bebbington, 1995). Changes in routine should be as gradual as possible, and caregivers should allow patients time to become familiar with such alterations to daily habits.

Significant sleep-activity disruption occurs even in the early stages of Alzheimer's disease (AD) and increases in severity with increasing disease severity (Bliwise et al., 1993; Vitiello, 1992). Both the physical and temporal environment can affect sleep patterns; however, alterations in circadian rhythm, which can arise from biological or environmental issues (see Module 3), are thought to contribute substantially to the disordered night-time sleep, disrupted sleep architecture and increased daytime napping observed in patients with dementia. The poor sleep pattern results in decreased quality of life for both patients and caregivers and significantly increases the anxiety and exhaustion of the caregiver. This leads to the common caregiver experience of the '36-hour day'.

Sleep is influenced by the amount, and timing, of light exposure. Satlin et al. (1992) administered evening bright-light pulses to patients with AD and disturbance in the sleep-wake cycle. After 1 week, an improvement in the clinical ratings of sleep wakefulness was observed in the majority of patients, with more severe sundowning at baseline predicting a greater clinical improvement.

An increase in daytime physical activity can improve circadian rhythms and be reflected in improved performance and sleep (van Someren et al., 1993). Activity programs including walking programs, may improve disruptive behaviors (Appendices A and C). Passive heating appears to affect sleep in ways similar to exercise. A warm bath in the late afternoon or early evening is known to decrease sleep onset latency and improves sleep quality in young adults. This improvement induced by passive body heating has also been observed in elderly females (Dorsey et al., 1996).

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- Establishment of a regular routing, regular physical activity, adequate exposure to light and passive body heating may be useful strategies for improving sleep disturbance.
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Management of the temporal environment is particularly important in strengthening the normal circadian propensity for sleep and wakefulness. A component of this is reinforcement of normal time-giving cues (zeitgebers) that help demarcate daytime activities from nighttime activities (Gillin and Byerley, 1990).

### Sleep hygiene programs

Sleep hygiene programs are generally based on strategies geared to strengthen circadian rhythm status by maximizing cues to the brain's time-keeping system in addition to creating the most favorable physical environment for sleep.

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- The National Institutes of Health (NIH) Development Conference Consensus Statement (NIH, 1990) notes that sleep hygiene is a common medical and lay treatment practice, the value of which should not be underestimated for the treatment and prevention of sleep disturbances.
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Recommendations of the Consensus Statement (NIH, 1990) include:

- maintaining regular bedtimes and rise times
- using the bedroom primarily for sleeping
- regular timing of meals
- avoiding alcohol, caffeine and nicotine
- reducing evening fluid intake
- engaging in a bedtime ritual
- minimizing light and noise at bedtime and throughout the night.

Certain medications (such as diuretics and some antidepressants) taken at night should also be avoided.

Reducing the time insomniac persons without dementia spend in bed improves numerous indicators of sleep quality (Freidman et al., 1991). The cornerstone of sleep restriction therapy is the belief that excessive time in bed perpetuates insomnia. Although it has been hypothesized that sleeping quality might be improved in patients with dementia by sleep restriction therapy, this is yet to be proven. In AD patients, it may be beneficial to take a consolidated afternoon nap (i.e., to work with the biphasic circadian sleepiness rhythm) rather than to attempt to override the endogenous sleep tendency (i.e., to work against the rhythm).

## **Sensory considerations**

Normal changes that occur with aging affect both visual and auditory perception. Sensory deficits are normal in healthy elderly individuals, but in people with dementia they are less likely to be evaluated and appropriately treated. It is important to keep in mind that in persons with dementia sensory deficits will be exacerbated compared with non-demented elderly individuals, because of difficulties with orientation due to cognitive impairment.

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- Patients with dementia may become fearful, anxious or restless because they cannot properly see or hear their environment. Thus, patients need to be examined routinely to evaluate vision and hearing.
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The pupils of elderly persons have decreased ability to accommodate and thus cannot adjust readily to dark environments. Also, the yellowing of the lens results in diminished ability to perceive different colors, an effect that has fewer consequences in environments incorporating brighter hues. In addition, cataracts and glaucoma, which develop commonly, can contribute to disorientation. Contrasts need to be more vivid to be discerned, especially where there is a possibility of falling e.g. stairs.

Hearing decrement often occurs and, if uncorrected, is associated with increased rates of paranoia in the elderly. Appropriate intervention, such as provision of a hearing aid, should be made if a hearing deficit is diagnosed; although patients with more advanced cognitive deficits may need assistance to ensure correct usage. It is important to remember that a demented person with a hearing impairment is less likely to communicate even if a hearing aid is prescribed, and also more likely to misplace or lose the aid or to use it inappropriately.

## **Nutritional considerations**

It has been reported that up to 92% of patients with dementia will experience significant weight loss compared with age-matched, non-demented controls. Patients with dementia may forget to

consume food in a timely manner and may not pay attention to hygienic storage of their food. Taking time to assist cognitively impaired patients with eating and reminding them to eat are therefore important.

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- The types of food that may be consumed (e.g., low fat, low salt diets) and consistency of food (e.g., mechanical soft diet) may contribute to under nutrition because these can be rather unappetizing, especially in institutional settings.
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Eating has significant social meaning. Patients with mild to moderate dementia may be reluctant to be part of social situations because of awareness of their deficits, especially if they also have a hearing or visual impairment. These patients should be given support and encouragement to join in, and, if possible, arrangements changed to better suit their needs.

Specific BPSD are associated with the risk of under nutrition in different ways (see box below).

When patients have altered perceptions they may stop eating because of paranoid and delusional ideation about food and fluids. Treatment of the underlying psychotic process will help.

Very apathetic, cognitively impaired patients may be at severe risk for weight loss, as they lack initiative to eat. Recognizing patients at risk, and taking time to help them at meal times, are essential.

Weight loss can occur in patients with aggressive behavior if they are intent on throwing all meals and fluids on the floor or at caregivers, and caregivers are reluctant to approach them to assist with feeding. Teaching caregivers ways to pacify these patients during meal times and not sticking rigidly to set meal times, thereby giving the patients more freedom of choice, can be helpful.

Persons with dementia who show BPSD of pacing and wandering often experience weight loss, although the loss cannot be attributed to increased activity per se. Such patients appear to consume as much food as their less restless counterparts. Help with weight maintenance can be achieved by:

- making food available for brief snacks
- using behavioral interventions aimed at decreasing agitation.
- paying attention to personal tastes i.e. ensuring that favorite foods are provided while foods that the individual always disliked are avoided

## ***Behavioral interventions***

When seeking to deal with BPSD using a behavior-modifying intervention, the following general approach may be beneficial (Teri and Logsdon, 1990):

- Identify the target BPSD
  - a clear definition of the problem to be addressed is the first step in modifying behavior. The more clearly caregivers can define the problem, the more likely it is that they will be able to identify an effective course of action
  - close collaboration with the caregiver is usually necessary to identify a specific problem
  - it is better to tackle one BPSD at a time.

- Gather information about the BPSD (see also Module 2)
  - how often does the BPSD occur?
  - when does it happen?
  - where does it happen most?
  - in whose presence does it occur?
  - ask the caregiver to record the answers to these questions over 1–2 weeks
  - daily diaries are useful to understand the occurrence, frequency and severity of a target BPSD and to help formulate treatment plans.
  
- Identify what happens before and after a target BPSD
  - although the caregiver's impression may be that the problem BPSD happens 'out of the blue', careful observation of events immediately preceding the behavior can identify trigger factors
  - BPSD are rarely simple – usually several factors are involved in triggering a behavior and the more caregivers understand the inter-relationship of these factors, the more likely they are to intervene successfully.
  
- Set realistic goals and make plans
  - involve the patient as much as possible and work with the caregiver to set treatment goals
  - start with a small achievable goal and proceed step by step
  - tailor the plan to the individual patient and caregiver
  - be practical and allow plenty of time for change to occur – do not expect major changes overnight
  - work with the caregiver to anticipate problems that might occur and how they might be solved
  - if possible, have the caregiver generate several alternative plans and then decide which one to try first.
  
- Encourage caregivers to reward themselves and others for achieving goals
  - it is very important for caregivers to reward themselves for achievements, no matter how small
  - the patient will also benefit from rewards for their achievements.
  
- Continually evaluate and modify plans
  - treatment plans need to be continually monitored to determine how successful they are
  - decide how you will ascertain whether the plan is working (e.g., by monitoring the number of times the BPSD occurs, or the length of time for which it occurs)
  - caregivers need to be consistent and flexible in carrying out plans – i.e. they need to persevere with a chosen approach initially, but should not persist to the point of confrontation if the approach is clearly not working
  - if strategy 'A' has not worked, the caregiver and the clinician need to implement strategy 'B' and so on.

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■ **The 36-Hour Day** written by Mace and Rabins (1991) is an excellent guide for caregivers. It provides practical guides and suggestions for caring for patients with dementia and coping with BPSD.

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### **For depression**

While behavioral interventions can alleviate mild depression, patients suffering from moderate and severe depression often require an antidepressant (see Module 6). Behavioral interventions and pharmacotherapy are therefore often used in combination (Teri, et al., 2000; Teri, et al., 1997).

### **Recommended strategies**

- Increase and encourage activities that the dementia patient can enjoy. A good way to begin is by identifying activities that the person enjoyed in the past and modifying them appropriately to the person's current level of functioning. Teri and Wagner (1992) have shown that pleasurable activities decrease depression in demented patients, utilizing a wide range of adjunctive experiences in the context of individual psychotherapy.
- Confirm that the activities the caregiver believes are enjoyable really are those that the patient enjoys. Consult the patient and observe his/her behavior.
- Plan pleasant activities to be conducted with someone whose company the patient enjoys, particularly if the person complains of feeling isolated or lonely:
  - Encourage the patient to talk about pleasant things, both past and present: turning someone's thoughts to happy events and helping them remember good things can cheer them (it can also make them feel more depressed thinking of what has gone before, and so a degree of sensitivity is required).
- Provide a bright and cheerful environment.
- Individualize all of the above approaches to the person's needs and situation.
- Take care to maintain the caregiver's mental and physical health – it is difficult and sometimes depressing to be constantly with someone who is depressed.

### **For agitation and aggression**

Behavioral interventions for agitation and aggression can be very helpful and in milder cases can defuse or prevent the aggressive behavior. In severe cases, however, a short-term pharmacological intervention (see Module 6) may be needed alone or in combination with the non-pharmacological intervention (Teri, et al., 2000). Many strategies have been tried (see references in Appendix B); results vary and different methods may suit different patients:

- ◆ music, especially if individualized to the person's previous tastes
- ◆ audio-tapes of family members talking to the person with dementia
- ◆ use of video-tapes
- ◆ hand massage
- ◆ therapeutic touch
- ◆ aromatherapy – e.g. lavender oil
- ◆ sensory integration
- ◆ enhanced social interaction

### **Recommended strategies**

- Intervene early – by recognizing a problem situation and intervening before it becomes a crisis, caregivers can avoid many instances of agitation and aggression.
- Try to keep the patient away from situations and individuals that are provoking.
- Encourage caregivers to use a reassuring and gentle voice – it can help to defuse a situation by calming the person.
- An agitated person should be approached slowly and calmly from the front. Caregivers should tell the person what they are going to do and try not to startle them.
- Use touch judiciously – sometimes a touch or a hug can be comforting to an agitated person, but for another it could be provoking.

- Use non-threatening postures when dealing with an agitated patient. Standing over a patient who is seated or in bed can be frightening and may provoke anger. Caregivers should bend from the knees, kneel or sit down so that they are at the patient's eye level.
- Distract the person with questions about the problem and gradually turn their attention to something unrelated and pleasant – change activities, go to another room and leave the situation for a while.
- Establish a calm, quiet environment (see pages 8–10).
- Avoid arguing and trying to reason while the patient is agitated – arguing almost always causes the agitation/aggression to escalate. Back off and avoid confrontation whenever possible.
- Avoid physical restraint wherever possible. Restraints can increase the patient's perception of threat and escalate agitation.
- Caregivers should always get help immediately if they are in danger. They should be given emergency numbers to call and be strongly encouraged to use them if they feel threatened.

### **For wandering**

There are many reasons for wandering(see also Module 2): aimless, purposeful (e.g. in order to abscond from residential care), as part of a general agitation, as a symptom of depression or even as reaction to medication, i.e. akathisia. Where no specific cause can be discovered and treated, behavioral interventions can play an important role in the management of wandering.

### **Recommended strategies**

- Confused persons will often forget that they are supposed to be at a particular place and so require frequent reassurance about where they are and why they are there.
- If a patient who is going to be moved is able to understand what is going on, involve him or her in planning the move and visit the new setting beforehand. In more severely confused patients, it may be easier not to introduce them gradually, but to make the move as quickly as possible and without any fuss.
- Day care centers and nursing homes have found that people adjust best, and are therefore less likely to wander, when:
  - they do not stay long for the first few visits
  - the caregiver stays with them the first few times
  - someone from the program visits them at home before the transition.
- If the person is getting lost, and can still read, understand and follow instructions, give him or her a pocket card. The instructions on the card should be simple and might include a reminder, 'Stay calm and don't walk away, or 'Call home'--and a telephone number. Different cards may be needed for different trips.
- Patients who wander should wear a bracelet with the statement 'Memory impaired'. A bracelet that is securely fastened, so the patient cannot remove it or slip it off, may be better than a necklace.

### **For repetitive questioning/mannerisms**

Repetition of questions or actions by confused people can be extremely irritating or distressing for caregivers; however, it is unlikely that either reasoning with the patient (which is generally futile) or confronting the patient (which can exacerbate the behavior) will be beneficial.

### **Recommended strategies**

- Consistently ignoring repeated questions can work with some patients, but it will upset others who may become angry because they were not answered.

- Sometimes the person may be unable to express what is actually worrying him or her. For example, if a patient continues to ask for someone who is dead, he or she may be trying to express a feeling of being lost:
  - caregivers can react to this emotional aspect, explaining that they will take care of the patient
  - they could also distract the patient, either by asking him or her about something related or unrelated.
- If a patient is continually repeating a task, he or she can be distracted by being given a new and specific task to perform. It is important that the caregiver does not appear to pressure the patient or sound upset; in such situations, a catastrophic reaction can be precipitated.
- Providing positive attention for more appropriate behaviors will encourage these behaviors.
- Occasionally, the patient responds only to agreement by caregivers or being distracted by a lie, for example, telling the patient a deceased friend or relative will be coming later.

### **Case study**

Mary, who has been in an Alzheimer unit for a 3-week period of respite care, is due to go home today. She repeatedly insists to the staff that she must go and collect her daughter from boarding school for the holidays. Mary knows that she is to see her daughter again today and that there is to be some sort of change in living arrangements.

Settling into the respite unit and now preparing to go home again may have exacerbated Mary's temporal disorientation. In these circumstances her agitation may be worsened if she is confronted or corrected. Instead, it is appropriate to reassure her that her daughter is coming directly to the unit and that they will be going home together. Once they get home and Mary settles back into her familiar surroundings, her orientation may well improve (Swanwick, 1995).

### **For inappropriate sexual behavior**

Inappropriate sexual behaviors in people with dementia are uncommon. More common is the incorrect belief that these occur in 'senile' people. It is important to consider that, however infrequent the occurrence, accidental self-exposure and aimless masturbation are behaviors that caregivers find distressing and embarrassing. Behaviors may occur because the patient has forgotten where he is, how to dress or the importance of being dressed. However, it is also important to consider that undressing may also occur if garments are uncomfortable, and handling of the genital area may occur if the patient has a urinary tract infection, itching or discomfort.

### **Recommended strategies**

- If a patient is undressed:
  - calmly bring the patient a robe and, matter-of-factly, help him or her to put it on.
- If a patient is found masturbating:
  - try not to act upset or distressed and avoid confrontations, as this may precipitate a catastrophic reaction
  - gently lead the person to a private place
  - distract the patient by providing something else to do
  - prevent future episodes by increasing involvement in on-going activities.

## ***Recreational, adjunctive and social therapies (See Appendix B)***

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- Unlike many medically ill patients in nursing homes who are frequently debilitated and inactive, patients with dementia are physically able to walk about and seek stimulation.
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In the past, the need for social and recreational therapies has been overlooked; however, such activities are now widely incorporated into the daily management of patients with dementia and BPSD. An activities program can provide structure to the patient's day, preserve remaining capabilities, minimize the consequences of cognitive and functional deficits, and create an environment for social interaction.

The efficacy of such a program was evaluated in a study by Rovner et al. (1996). Each day, from about 10 a.m. to 3 p.m., patients in the intervention group were taken to an activities room in the nursing home where they engaged in various physical and social activities. The study supported the use of such interventions to reduce the prevalence of BPSD and the need for restraints or psychotropic medication.

Gerdner [2000] reviewed the literature of similar interventions. This review indicates that, for patients with dementia, music has the strongest research base, although a number of recent studies have begun to determine the impact of other recreational therapies. Music, reality orientation, reminiscence, and validation therapies have all been the subject of Cochrane database systematic reviews. The strongest evidence was found for reality orientation [Spector et al., 2000a]. Reviews of music [Koger and Brotons, 2000], reminiscence [Spector et al., 2000b], and validation [Neal and Briggs, 2000] therapies were not able to identify reliable statistical evidence of significant impact but were suggestive of beneficial effects in treating or managing dementia symptoms. The predominant conclusion of these reviews is the need for additional well-designed studies of such interventions.

### **Music therapy**

Research shows that **background music** reduces anxiety for a wide range of medical illnesses (including post surgical coronary care patients, obstetric or arthroscopic surgery patients and dental patients [post surgery]) and reduces nausea and vomiting in cancer chemotherapy patients. Background music also has been shown to decrease persistent auditory hallucinations in patients with chronic schizophrenia.

Because the neostriatum, which is involved in musical memory and coordination, is one of the last parts of the brain to deteriorate in AD, even patients with severe AD may retain musical abilities and the capacity to participate in musical activity. Thus, it is reasonable to expect that background music will allay anxiety and decrease agitation for patients with BPSD, although research has yet to determine how often music needs to be played and for how long a period. Preliminary evidence suggests that the most effective music is non-heavily percussive, from the patient's teen years, and from his or her own country. Music tailored to the patient's individual tastes is more effective in reducing agitation (Gerdner et al, 1999)

**Music therapy** can lead to:

- reduction in anxiety and restlessness
- sleep induction
- reduction in hostility.

Specific techniques include:

- providing simple musical accompaniments
- moving or dancing to music

- stress reduction through music (Hanser, 1996.).

### **Other therapies**

Anecdotal reports have suggested that a number of other activities and therapies are helpful for some patients, although, to date, no studies have been performed to evaluate this systematically.

Examples of these adjunctive approaches are:

- religious activities
- pet therapy
- art therapy
- movement therapy.

## ***Psychological interventions***

### **Individual psychotherapies**

Many patients need help structuring their lives, giving up previous activities, and becoming involved with activities that they still have the capacity to perform. They may also need assistance acknowledging their fearfulness of being exposed to social situations and in overcoming these anxieties or adjusting to a reduction in their social life.

Patients with early and mild AD can benefit from individual psychotherapy. Many are frightened about their cognitive losses and have insight to realize the nature of their problems. Later on in the illness, denial is more prominent, and insight is commonly lost. Patients can benefit from an empathic and information-driven approach that helps them to focus on their feelings, the practical aspects of their illness and their mourning response to their cognitive deficits.

The most important factor in successful psychotherapy is the capacity to form an affective attachment. Many patients develop an idealized transference with the therapist and feel protected and less anxious knowing that the therapist is available (Finkel, 1979).

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- Caregivers will report that even though a patient may not remember the details of the session, the empathic relationship and sense of reassurance can result in the patient being calmer for hours or even days following the session.
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When patients embark on an individual course of psychotherapy, a comprehensive evaluation must take place. A complete history should be taken and incorporated with information provided by caregivers. This information is especially important in adapting psychotherapeutic interventions.

### **Family psychotherapy**

The decline of a parent's cognitive function represents a crisis for the entire family. Even for the closest of families, it may create tensions and conflicts, although these are customarily resolved. For those families where certain members are alienated, the crisis can result in renewed contact, which, in turn, leads to opportunities to resolve old family conflicts, or results in additional

fragmentation and hostility, often with disastrous consequences. Often old sibling conflicts are revived.

Family members will respond to this loss of a parent (which is accompanied by the sense of loss of a powerful individual who is protective and nurturing) in vastly different ways. For some it causes great panic, others use denial, some accept this in a matter-of-fact way, while some families are drawn more closely together as they struggle to deal with the BPSD. The family requires information about the illness, as well as techniques for dealing with a range of management problems.

It is best to meet with all family members together. If certain siblings are not present, they may be the ones that have difficulty with the consensus recommendations. Typically, it is best to see the family at the last session of the day, for two reasons:

- there may be few opportunities to get everybody together
- once members become involved, discussions may last for a considerable period of time before resolution.

Caregivers, especially the primary caregiver, need a great deal of encouragement to maintain a life outside caring for the person with dementia (see also Module 4). Caregivers are at particular risk of developing major depression and a number of stress-related illnesses (e.g., hypertension, ulcers). Often caregivers will feel guilty about taking care of themselves, and it is important to assure them that when they take care of themselves, they are actually taking care of the ill family member. If they are strong and healthy, they are in the best position to maintain their current life situation. It is not uncommon for caregivers to also feel guilty when they require additional services. This can begin with sitters, leading to adult daycare services, and eventually nursing home placements. Caregivers also need help in dealing with their anger, both at their demented family member, as well as with their life circumstances (see box).

- Psychosocial interventions should be tailored to the individual needs of patients, families and caregivers. Such interventions need to be modified as individual needs change during the course of the illness and involve helping them to accept the diagnosis and deal with realistic limitations
- ensuring issues revolving around finances, which can lead to agitation, are understood and dealt with realistically
- adapting effective coping strategies (e.g., knowing when to insist on a patient's cooperation and when to back off)
- accepting role changes, especially increasing dependence
- altering environments so they are less likely to be traumatic to the patient and thus less likely to result in BPSD
- obtaining more informal and formal support (possibly including support groups from a local AD association)
- dealing effectively with issues surrounding other caregivers who may have their own ideas about treatment strategies.
- As the illness progresses, the caregiver will need help in the grieving process and with ethical issues involving conflict between safety and allowing autonomy.

### **Group psychotherapy**

Early studies of group therapy conducted in patients who were demented demonstrate that patients with very early or mild AD can benefit from group contact with others who face similar circumstances and have similar emotional challenges dealing with their cognitive loss (Yale, 1995).

Mixing together patients with depression and dementia does not work well because depressed patients feel threatened and those with cognitive deficits feel intimidated by their comparative lack of cognitive abilities. This aside, discussing one's feelings, clarifying issues, finding ways to direct activities, and dealing with loss under the supervision of an experienced therapist are important components of treatment and facilitate adjustment and improved quality-of-life. Information to date on group therapy for demented individuals is, however, based on clinical description and anecdotal information, rather than on proved research.

### **Team approach**

Several studies, principally in residential care settings, have demonstrated that a team approach and provision of consultancy can significantly decrease challenging behaviors. This may involve case management, implementation of individual treatment programs, nurse education or behavioral management strategies or a combination of these.

### ***Conclusion***

Behavioral and psychological symptoms are ubiquitous in dementia. Many non-pharmacological strategies are effective in reducing, eliminating or even preventing these behaviors. The focus may be on the environment, the staff, the family or the patient. More often it is a combination of different approaches. The challenge is not the behavior but its management. Meeting the challenge requires creativity, ingenuity often and empathy - a humane understanding of the world of the person with dementia. Frequently several approaches are required before the successful one is discovered. A team approach involving professionals, all residential staff (including non-clinical and domestic staff) and families is best. Physicians have an important role in excluding other causes of BPSD (see module 2) and in being part of the management team.

## **Appendix A: Sample nursing care plans for patients with BPSD**

This appendix includes some useful examples of ways in which care plans incorporate different non-pharmacological interventions in the management of patients with BPSD.

### **Nursing diagnosis: Sensory perceptual alteration (visual, auditory, tactile)**

Signs and symptoms: Hallucinations, delusions, and disorientation.

<b>Intervention</b>	<b>Rationale</b>
Express concern and care for the agitated patient. Remain close by until the patient becomes calm.	These measures provide support and help relieve the patient's fears.
Allow the patient to express thoughts, continue talking with them and express concern while maintaining eye contact.	Comforting a patient often helps alleviate the delusions or hallucinations.
Keep a night light in the patient's room.	Agitation and hallucinations may worsen at night because of perceptual disturbances. Use of a night light can be soothing.
Remove extraneous stimuli, such as televisions and radios, from the environment if necessary.	Extraneous stimuli may initiate visual, auditory or tactile hallucinations or impair the patient's ability to receive important stimuli.

#### Outcome criteria:

- the patient will not become agitated
- the patient will function safely within the environment.

**Nursing diagnosis: potential for violence directed at others**

Signs and symptoms: Demanding attention, committing overtly aggressive acts, accusing others falsely.

<b>Intervention</b>	<b>Rationale</b>
Exclude pain or physical discomfort as a cause of violent behavior during assistance with dressing, toileting etc,	In severe dementia, hitting out may be the only means of communication when the patient has pain [e.g. on moving an arthritic joint during dressing]
Listen actively to the patient, remain honest, calm, clear and concise during interactions. Ensure appropriate eye contact and facial expressions.	This establishes a sense of trust, conveys attention and concern and facilitates communication.
Do not rush the patient or overly structure the environment.	Tension commonly results from feelings of being forced or pushed to act in a certain way.
Remove all potentially harmful items from the patient's reach.	The patient may use objects within the environment to injure others.
Reinforce non-violent behavior	Rewarding positive behaviors discourages negative outbursts.
Encourage the patient to do as much as possible for him or herself.	Invading the patient's personal space may cause physical aggression.
Promote regular exercise.	Regular exercise helps control and channel the patient's energies.
Avoid arguing or trying to reason with the patient.	The patient cannot appreciate another point of view at such times.
Do not use aggression or make threats when dealing with patients.	A calm approach is important in reducing the potential for aggression.

**Outcome criteria:**

- the patient will begin to control the behavior with the assistance of others
- the patient will have fewer violent responses.

**Nursing diagnosis: altered patterns of sexual behavior related to cognitive impairment**

Signs and symptoms: Inappropriate sexual activity, confusion about inappropriate behavior, sexual exposure.

<b>Intervention</b>	<b>Rationale</b>
If the patient makes inappropriate advances, casually refuse their overtures, then try to distract them. Avoid negative overreactions.	The patient with cognitive impairment typically loses the capacity to understand social rules. Avoiding overreactions helps prevent violent or verbal abusive episodes.
If the patient undresses in public, change clothing type or fasteners (e.g. buttons at the back of a garment, rather than the front).	Altering clothing style decreases the risk of inappropriate exposure.
If the patient masturbates in public, distract and remove him or her from the area.	Such behavior often embarrasses people or staff observing it.
Encourage the patient to participate in physical activities.	This will direct sexual energy toward productive physical activity, thereby reducing the potential for inappropriate sexual behavior.

Outcome criteria:

- staff will implement measures to prevent or reduce the incidences of inappropriate sexual behavior
- staff will cope effectively with the patient's sexual behavior
- the patient will have an outlet for sexual feelings and needs.

## **Appendix B: Recreational adjunctive and social therapies**

(Burns, 2002, Gerdner, 2000; Opie et al, 1999) with additional references\*

### **PHYSICAL ENVIRONMENT**

<b>Authors</b>	<b>Target BPSD</b>	<b>Intervention</b>	<b>Main results</b>
Chafetz et al 1990	Exiting behavior	Strips of contrasting colored tape laid on floor before doors	Exiting behavior not decreased
Cohen-Mansfield & Werner, 1998	Agitation, pacing, trespassing and exiting	"Nature scene" and "Home and people" environments created in nursing home corridors	Significant increase in time spent in enhanced environments, non-significant reductions in trespassing, exiting and agitation
Dickinson et al, 1995	Exiting behavior	Door obscured by same color blind or cotton sheet	Exiting behavior decreased
Mayer & Darby, 1991	Physical contact with door	Full-length mirror in front of door	Decrease in physical contact with door
Namazi et al, 1989	Exiting behavior	7 types of visual barrier – colored strips of tape, hiding doorknobs using cloth, paint or secure cover	Tape increased exiting, other interventions decreased exiting
Negley & Manley, 1990	Aggression during elevator transfer to meal room	Meals provided in day rooms (making transfer unnecessary)	Assaults reduced
Whall et al, 1997	Agitation and aggression during bathing	Bathrooms enhanced with tape recordings of birdsong, flowing water and small animals and large bright pictures, residents offered pudding and soft drinks, nursing aides trained	Significant decline in agitation and aggression

### **ACTIVITY PROGRAMS**

<b>Authors</b>	<b>Target BPSD</b>	<b>Intervention</b>	<b>Main results</b>
Cohen-Mansfield & Werner, 1997	Verbal disruption	Audiotapes of preferred music Video tapes of family members talking to the older person Social interaction	Significant decreases in verbally disruptive behaviors compared to control non-intervention
Holmberg, 1997	Wandering	90 minute walking program weeknights	Significant drop in aggressive incidents
Namazi et al, 1994	Agitation	Daily 40-minute physical activity program	Agitation episodes decreased significantly compared to controls
Robichand et al, 1994	Agitation	Sensory integration training for residents	Non-significant improvements in both groups
Zisselman et al., 1996	Behavioral disturbances	Persons assigned to a pet therapy intervention group or an exercise control group for 1 hour per day, 5 consecutive days	No significant differences between or within groups before and after the intervention

## MUSIC, VOICE AND LANGUAGE

<b>Authors</b>	<b>Target BPSD</b>	<b>Intervention</b>	<b>Main results</b>
Burgio et al., 1996	Verbal agitation	Audiotapes of babbling brooks or ocean waves, preferred music	Decreased verbal agitation
Camberg et al., 1999*	Agitated or withdrawn behaviors	Audiotape by family members or staff of memories in the format of a telephone conversation compared to audiotapes of emotionally neutral newspaper articles and usual care	Significant reduction in staff reports of agitation and withdrawn behaviors compared to controls, but not on direct observations
Clark et al., 1998	Aggression	Audiotapes of preferred music played during bath times	Significant reduction in aggressive behaviors
Denny, 1997	Agitation	Classical music played for 1 ½ hours in the dining room during the noon meal during alternating weeks	Statistically significant reduction in agitated behaviors during the presentation of music
Devereaux, 1997	Agitation	Individualized or preferred music played for 30 minutes on 5 consecutive days for 1 week	Reduction in agitation during the intervention and the 30 minutes immediately after the intervention
Gerdner et al., 1999	Agitation	30 minute audiotapes of individualized music or classical relaxation music twice a week for 6 weeks	Significant reduction in agitation during and following individualized music compared to classical
Hall & Hare, 1997	Agitation	A commercially prepared video that incorporates “familiar music” and “common memories” was presented.	No significant difference in agitated behavior. A slight increase in positive behavior reported during the observation period.
Ragneskog, et al., 1996	Agitation/ Depression	Music played from five minutes before dinner until last person left dining room	Increased food intake during music, particularly for desert; reduction in irritability, fear-panic, and depressed mood
Remington, 1999	Agitation	Persons assigned randomly to one group: 1) calming music; 2) hand massage; 3) calming music and hand massage; 4) control.	Each experimental intervention produced a significant reduction in agitation compared with the control group. The benefit was sustained and increased over time.
Tabloski, et al., 1995	Agitation	Two 15-minute presentations of music (Pachelbel's Canon in D) approximately one week apart	Reduction in agitation during and after the music intervention
Thomas et al., 1997	Aggression	Selected music based on the patient's personal preference as reported by a family member	Significant reduction in aggressive behavior but, hiding/hoarding, physically non-aggressive and, verbally agitated behavior not reduced.
Woods & Ashley, 1995	Problem behaviors	Audiotapes by family members recounting cherished memories played twice a day	Problem behaviors reduced significantly while tapes were played

## BEHAVIOR THERAPY

Authors	Target BPSD	Intervention	Main results
Bird et al, 1995	Individual problematic behaviors	Cued recall – signs and staff involvement	Reduction in problematic behaviors
Doyle et al, 1997	Disruptive vocalization	Contingent reinforcement rewarding quiet behavior, ignoring outbursts and distraction with music, conversation, touch or visual aids	Significant reduction in noisiness
Gormley et al, 2001*	Aggression	Four session behavioral management training for caregivers in their own homes compared to 4 sessions of discussion on care-related issues	Non significant trend towards reduction in aggressive behavior in behavioral management group
Moniz-Cook et al, 2001*	Aggression and agitation	Systematic analysis and targeted intervention involving nursing home staff	Reduction in aggression and agitation
Teri et al, 2000*	Agitation	8 weekly and 3 biweekly structured behavioral management training sessions for caregivers compared to haloperidol, trazodone and placebo	No significant differences between haloperidol, trazodone, behavioral management and placebo. Modest reductions in agitation in all groups

## MASSAGE AND AROMA

Authors	Target BPSD	Intervention	Main results
Ballard et al, 2001	Agitation	Melissa oil (10% by weight combined with base lotion) via cream applied to hands twice daily	Significant improvement as measured by Cohen Mansfield agitation inventory
Brooker et al, 1997	Agitation	Series of 30-minute hand massage or lavender aromatherapy	¼improved, 2/4 worsened
Holmes, et al, 2002	Agitation	2% lavender oil via aromatherapy stream daily	Significant improvement as measured by Philadelphia agitation scale, with 60% of patients having some benefit
Smallwood et al, 2001*	Behavior disturbance	Aromatherapy + massage, plain oil massage and conversation + aroma compared	Aromatherapy + massage showed greatest reduction in agitation significant between 3-4pm compared to conversation + aromatherapy
Snyder et al, 1995	Agitation	10-minute hand massage and therapeutic touch	No reduction in agitated behaviors
Snyder et al, 1995	Agitation	Hand massage twice a day	Significant reduction in agitation, though not all behaviors reduced, effect only in females

## LIGHT THERAPY

Authors	Target BPSD	Intervention	Main results
Colenda et al, 1997	Sundowning	2 hour morning exposures to 2000lx light worn on the head 3-4 cm from the eye	No reduction in agitation
Graf et al, 2001	Sundowning	Randomized evening bright light or dim light therapy	Increase in mini-mental state exam scores and phase shift in body temperature rhythm
Haffmans et al, 2001*	Agitation	2X5 consecutive morning exposures to 30-minutes 10,000lx bright light and randomly administered 2.5gm melatonin or placebo at 22.00h	Bright light 30 +/- placebo showed significant decrease in agitation, but no reduction in melatonin group
Lovell et al, 1995	Sundowning	2hour morning exposures to 2500 white fluorescent light	Significant reduction in evening agitation
Lyketsos et al, 1999*	Agitation	1 hour morning exposure to 10,000 lx bright light for 4 weeks	Length of sleep of residents improved significantly. No change in other behaviors
Satlin et al, 1992	Sundowning	3 hours evening exposures to 1500-200lx fluorescent light for a week	Reduction in restlessness that increased again after treatment was stopped

## MULTI-DISCIPLINARY TEAMS

Authors	Target BPSD	Intervention	Main results
Brody et al, in press*	Depression and Psychosis	Psychogeriatric case management included psychotropic management, supportive therapy, pleasurable activities and behavior management compared to consultation or standard care	No significant differences between groups. Subjects in all groups improved.
Hinchliffe et al, 1995	Behavioral disturbance	Team implementation of individually tailored treatments including psychotropic medications, activities, behavioral strategies and carer education	Significant improvement in 15/20 of intervention group, but only 2/13 of wait-list group improved after intervention
Hughs & Medina-Walpole, 2000*	Behavioral disturbance	Team management including systematic behavioral observation, pharmacological and non-pharmacological interventions.	Reduction in behavioral disturbance (partly attributed to better medication use)
Opie et al, 2002*	Challenging behaviors	4-week team management including psychosocial strategies, nursing approaches, psychotropic medication and pain management	Consultancies significantly significant decrease in challenging behavior compared to controls. Both groups improved.
Proctor et al, 1999*	Behavioral disturbance	Seminars for care staff by outreach team, weekly visits from psychiatric nurse.	Significant improvement in depression, but not on behavioral rating

Rovner et al, 1996*	Behavioral disturbance	Program included activities, guidelines for psychotropic medications and educational rounds	Significant reduction in prevalence of behavioral disorder compared to controls
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## CARER EDUCATION

Authors	Target BPSD	Intervention	Main results
Bourgeois et al, 1997	Repetitive verbalizations	Training family carers to use individualized written cues to prompt memory. Included 3-hour behavioral management principle workshop and 11 1-hr weekly home visits.	Significant decrease in repetitive verbalizations
Burgener et al, 1998	Behavioral disturbance	Carer education on behavior	Statistically insignificant reduction in behavior
Hagen & Sayers, 1995	Aggression	Three 30-minute in-services for hospital staff (including housekeeping and recreational staff)	Significant reduction in incidents of resident aggression
Haupt et al, 2000*	Agitation and anxiety	12 weekly 90-minute group psycho-education for caregivers	Significant improvement in agitation and anxiety
Matthews et al, 1996	Behavioral disturbance	Workshops on client-oriented approaches, residents given freedom to rise from bed, take their meals and participate in activities	No changes in aggression and non-physical agitation, daytime sleep increased, verbal disruption in the mornings decreased

## PSYCHOLOGICAL THERAPIES

Authors	Target BPSD	Intervention	Main results
Baines et al, 1987*	Problem behaviors	Reminiscence groups	Reduction in problem behaviors
Fine & Rouse-Bane, 1995	Difficult behaviors	Care staff trained in validation therapy – listening, distraction, eye contact, emotional expression and other techniques	Reduction of reported incidents attributable to difficult behaviors of 3%
Gibson 1994*	Behavioral disturbance & agitation	Reminiscence groups – both dementia specific and mixed (for any residential care resident)	Behavioral disturbance rare in mixed groups. Staff report less agitation for some individuals outside group.
Gibson 1994*	Troubled or troubling	Individualized care plan including reminiscence therapy	Decreased aggression and demanding behaviors
Goldwasser et al, 1987*	Behavior and depression	Twice-weekly reminiscence and support groups for 5 weeks	No differences on behavior between intervention and no-treatment controls. Significant reduction in depression post-intervention, but lost at 6-week follow-up

Welden & Yesavage, 1982*	Behavioral problems	Relaxation instructions including progressive muscle relaxation and self-hypnosis techniques	Significant improvement compared to discussion group controls. 40% no longer required sleeping tablets
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