

6 Management of dementia

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*Historical context • Structured approach • Treatable causes of dementia
• Concurrent illness • Troublesome behaviours • Medication •
Psychological interventions • Social interventions • Carers • Primary
health care • Multi-disciplinary team • Care Programme Approach •
Problem-orientated approach • Conclusion*

There are no simple recipes for managing dementia. Imagination is required to find solutions to the various problems. However, imagination needs structure, and ideas with which to play. It is the purpose of this chapter to offer these.

Historical context

The 'mere oblivion' of Shakespeare's seventh age, to which dementia as well as sensory impairment must have contributed, has always been a fate threatening those few men and women who survived into their eighth decade. Until the present century they were so scarce as to present little or no problem to society as a whole, though they may have been a burden on some families. Extended families, where three generations lived within a mile or so of each other, coped with their frailer elders, if they were not too disabled or deranged. Otherwise there were, for the poor, workhouses and asylums. The former were gradually replaced by local authority homes under Part III of the National Assistance Act, while the latter were used for those with 'senile dementia' unable to give informed consent to institutional care, who were compulsorily admitted (a procedure involving a magistrate) under the Lunacy Act.

The 20th century has seen the remarkable ageing of populations in the developed countries, so that those over 65 years of age in the UK have grown from 5 to 17% of the population. The burden of ageing and dementia has vastly increased, and resources have changed. Families continue to offer most support, but health services (including the specialities of geriatrics and the psychiatry of old age), social services and voluntary organisations have developed. Recent genetic and pharmacological advances in Alzheimer's disease may herald more resources and better care for those with dementia and their carers.

Structured approach

Box 6.1 gives a simple, four-point check-list as an initial approach to management, using the mnemonic DIPS (Burns & Hope, 1997). In practice, treatable causes of dementia are uncommon, and treating concurrent illnesses usually leaves several problems unsolved. Constructing a list of problems is often the most valuable part of the assessment. These problems are prioritised; it is unlikely that all problems can be tackled at once. An overall perspective should be maintained. For example, one patient displayed a large number of behavioural difficulties; but the key problem was her daughter's guilt at the thought of her moving to an old people's home. Once the problem list is made, solutions to the most pressing problems are generated. It is important to support the carer and involve them in the management plans as far as possible.

Treatable causes of dementia

The management of dementia starts with a full assessment of the patient. This includes a history, mental state examination, physical examination and investigations (see Chapter 1). It is helpful to speak to an informant such as a carer, as well as gathering information from other services including the general practitioner (GP) and social services. The assessment aims initially at excluding other conditions such as delirium or depression, and arriving at the type of dementia syndrome. It is particularly important to exclude the treatable causes of dementia (see Chapter 5). These are reviewed in Lishman (1998).

Concurrent illness

People with dementia are not immune from other illness and disability. However, dementia may mask the symptoms and interfere with eliciting signs. Any alteration in behaviour in someone suffering from dementia may be the result of concurrent illness (Granacher, 1982; Moss *et al*, 1987; O'Connor, 1987). Box 6.2 lists important conditions and disabilities.

Box 6.1 DIPS: a structured approach to management of dementia

Dementia: treat the cause where possible
Illness: treat concurrent illness
Problem list: tackle each major problem
Support the supporters: care for the carers

Box 6.2 Concurrent illness and disability

Physical illness and symptoms

Infection (e.g. chest, urine)

Metabolic disturbance (e.g. dehydration, diabetes, renal failure, liver failure)

Cardiac failure or anaemia

Drug toxicity

Hypothermia

Malnutrition

Constipation

Pain

Symptoms of mental illness

Depression

Delusions or hallucinations

Anxiety

Disabilities

Poor hearing or vision

Dental problems

Foot problems

Incontinence

Depression

Depression commonly accompanies dementia, and may benefit from treatment in its own right. Assessment can be difficult if the dementia is too severe for patients to give a good account of their mood and thoughts. In these circumstances, fearfulness and the appearance of sadness may be useful indicators of depression. It may be possible to gain some access to the thoughts of people with moderate dementia, by paying attention to the content of spontaneous speech. The Depressive Signs Scale (Katona & Aldridge, 1985) rates depression in people with dementia (Box 6.3). The nine items are useful indicators of depression in patients with dementia. A history of depressive illness increases suspicion of a present depression.

Two principles should be followed in prescribing antidepressant medication: proceed cautiously using relatively safe drugs with few side-effects (e.g. fluoxetine, lofepramine or trazodone) and define clearly the criteria for success or failure. For further discussion of antidepressant medication and dementia see Satlin & Cole (1988).

Delusions and hallucinations

Delusions and hallucinations commonly occur in the course of dementia (Table 6.1). Often delusions take the form of paranoia where the patient

**Box 6.3 Items associated with depression in dementia
(Katona & Aldridge, 1985)**

A sad appearance
 Alleviation of sad appearance by external circumstances
 Agitation
 Slowness of movement
 Slowness of speech
 Early wakening
 Loss of appetite
 Diurnal variation in mood
 Loss of interest in surroundings

accuses people of stealing something they have mislaid. A gentle approach usually proves helpful in these circumstances. Visual hallucinations should raise suspicion of an added delirium or dementia with Lewy bodies. For psychotic symptoms which are persistent, and disturbing for the patient, antipsychotic medication may help (see Chapter 16). Particular care should be taken to prescribe the lowest effective dose of neuroleptic, and to closely monitor for side-effects.

Troublesome behaviours

There are a range of troublesome behaviours which may be identified from the history (Table 6.1). These should be listed, and strategies generated to deal with them. Carers often find these behaviours particularly difficult to deal with and stressful (see Chapter 18).

Table 6.1 The frequency of troublesome behaviours found in a sample of patients with dementia (Swearer *et al*, 1988)

	%
Angry outbursts	51
Dietary change	46
Sleep disturbance	45
Paranoia	32
Phobia	25
Delusions and hallucinations	22
Assaultative/violent behaviour	21
Bizarre behaviour	21
Incontinence	17

Aggression

Overt, directed aggression is rare in dementia. What is far more common is irritability or anger at being disturbed at times of washing, dressing or eating. At home this anger is usually directed at carers, while in institutions, staff or other residents may be on the receiving end. Aggression needs a considered response:

- (a) Maintain an unhurried, friendly and respectful manner.
- (b) Exclude obvious causes of anger such as pain, depression, psychosis or nicotine withdrawal.
- (c) Use a behavioural approach like ABC (see below)
- (d) Distraction may be helpful.
- (e) A short period of 'time out' is justified as part of a behavioural programme.
- (f) A very small dose of a neuroleptic can be effective, but avoid sedation.

Wandering

Wandering may result from many causes and the management depends on the cause (Box 6.4). Often a more structured and fuller day is required and the person may require more interaction. The design of the environment can have an important effect. Sometimes it may be necessary to lock doors. Physical restraint should be avoided if possible. Medication may be helpful for anxiety, depression or psychosis but its use as a 'chemical straitjacket' should also be avoided. It needs to be closely monitored and stopped if failing or harmful.

Restlessness at night

Patients with dementia often become more agitated and confused at night (sundowning). Their sleep cycle may become so disturbed that they are up all night and sleep during the day. They may find the quietness and darkness of night threatening. Delirium should be excluded. Efforts should

Box 6.4 Causes of wandering

Boredom and lack of stimulation
Lack of exercise
Habit
Anxiety, agitation, depression or psychosis
Seeking out somewhere such as the shops or home
Pain or discomfort

be directed at ensuring rewarding activities (and little sleep) during the day. This is often easier said than done. Other advice is to establish a routine with a fixed bedtime late in the evening, avoid stimulants such as tea and coffee, encourage a reasonable sized meal a few hours before bedtime, and to make sure the bed is warm and comfortable. If these measures fail then medication may help. This could be a neuroleptic such as thioridazine, a sedating antidepressant such as trazodone, or a hypnotic such as temazepam or chlormethiazole (see Chapter 16).

Incontinence

Incontinence has many causes (Box 6.5). Those associated with dementia include poor planning, disorientation, being unable to recognise the toilet, not caring, and less cortical control of bladder or bowel. Management depends upon the cause. Measures include:

- (a) regular visits to the toilet especially before travelling;
- (b) clear labelling of a convenient toilet;
- (c) avoiding drinks before bedtime;
- (d) treating constipation or urinary tract infections;
- (e) incontinence pads; and
- (f) an anticholinergic for an unstable bladder (be wary of hastening cognitive decline).

Sexual disinhibition

This is often stressful for carers (see Chapter 18). Behaviour includes exposing self, extreme sexual language, masturbation and propositioning others. It is important not to reinforce the behaviour, and a behavioural approach may be helpful. Rarely it can be necessary to use a libido suppressant such as benperidol, as an alternative to secure or single gender institutionalised care (see also Chapter 11).

Box 6.5 Causes of incontinence

Stress incontinence
 Immobility
 Urgency associated with prostatism
 Urinary tract infection
 Over sedation
 Diabetes
 Diuretics
 Epilepsy

Uncooperativeness

Ideally all management plans, including attending day centres or hospital admission, should be discussed with the patient and agreement reached. However, services are sometimes rejected by patients who may refuse any help, or expect their carer to offer all the support. At other times, patients with dementia may refuse medication or hospital admission. In these circumstances, it is best to explain the situation clearly and calmly to the patient, and try not to be too confrontational. Gentle persuasion or leaving the discussion for a little while can be effective. Some ideas sound more acceptable from doctors than carers, and vice versa. A visit to a day centre may relieve fears for the patient and carer. Medication, such as a small dose of neuroleptic, may relieve some of the anxiety associated with change.

Use of legislation is usually reserved for those situations where it is felt the patient is putting themselves at risk. The Mental Health Act (1983) can be used in order to assess and treat someone in hospital compulsorily. Similarly, guardianship is sometimes used to require someone to live at a specific place such as a residential home (see Chapter 19). In practice, many people with dementia are admitted to hospital or residential care without real consent.

Medication

There are two broad categories of medication used in dementia: drugs aimed at improving cognitive function; and drugs aimed at reducing problematic behaviour. These approaches are considered separately in Chapter 16.

Psychological interventions

Psychological treatments have emphasised the importance of a structured approach to solving specific problems, and have provided a much needed reminder that a person with dementia has experiences and wishes which should be respected. Treatments can be broadly divided into therapies for dementia and therapies aimed at specific problems. The general therapies of reality orientation, reminiscence, validation therapy, memory therapy and resolution therapy are covered in Chapter 17. Therapies aimed at specific problems are described in the following section. Garland (1997) provides a good review of the applications of psychological treatments to elderly people, including those with dementia.

Behavioural analysis

One of the most important contributions of psychology to the management of dementia has been the development of a structured approach to tackling behavioural problems. It involves three stages:

- (a) Observing what events and situations *activate* (or are *antecedent* to) the behaviour.
- (b) The *behaviour* itself is precisely described.
- (c) Identify the *consequences* of the behaviour (for example, how carers respond).

This approach is usefully known as the ABC analysis of behaviour. Stokes (1990) gave an example of aggressive behaviour. The first step involves finding out when and where the behaviour takes place, what the person was doing immediately before the aggression and what else was happening around this time. The second step means describing exactly what the person did. The third step identifies how the victim, and other people reacted, and how the aggressor responded.

Usually a period of at least several days' structured observation is required before any therapeutic interventions are introduced. The effectiveness of these is then assessed through further observations. The interventions may involve reducing the likelihood of the person being in the provoking situations, they may be aimed at altering the responses of other people or they may involve a combination of the two.

Strengths-based approach

A focus on solving problems needs to be tempered by a strengths-based approach which emphasises the importance, in therapy, of capitalising on what the individual patient can do and enjoy.

Social interventions

Social treatments involve changing the environment of the person and helping those who are principally involved in the care. Good reviews of these treatment strategies are provided by Moriarty & Levin (1993), Morris & Morris (1993), Bradshaw (1997), Levin (1997) and Moore & Buckland (1997).

Restructuring the environment

This looks at how the environment can be: made more safe; altered to enable the person to cope better; and be pleasant and stimulating.

Safety

Box 6.6 is a check-list of some of the ways in which people with dementia might be unsafe and come to harm. A patient's safety needs to be kept under regular review, particularly in the light of increasing impairment. Maintaining a balance between safety and the restriction of a patient's

Box 6.6 Ways in which people with dementia can come to harm

Falling on slippery floors
Falling down stairs
Falling from bed onto hard floor or against furniture
Starting fire with matches, candles or cooker
Scalding with hot tap water or kettle
Wandering away and spending night outside or hit by traffic
Choking
Unsuitable ingestion of medication
Abuse from carer

freedom is one of the most difficult aspects of caring for people with dementia. For example, people who wander off from their home are often at some risk of being hit by traffic. However, the degree of restriction which would prevent this behaviour may interfere greatly with the freedom enjoyed by both patient and carer.

Coping better

The environment should be reviewed to help the patient cope with problems. Some simple examples of environmental manipulations are summarised in Box 6.7. More sophisticated measures include radio-tagging devices to ensure that someone cannot get lost if they wander off (McShane *et al*, 1994), and floor designs in front of exit doorways, which are thought to decrease the chance of confused people leaving the ward (Hussian & Brown, 1987).

Pleasant and stimulating

A discussion of the environment should not concentrate exclusively on solving problems. It is also important to design an environment which is

Box 6.7 Environmental manipulations to help patients to cope

Clear labelling of toilet rooms
Maintain consistent furniture arrangement
Enable carers to develop one-to-one relationships with patient
Maintain adequate lighting in all areas used by patients
Use identification necklace for those who wander off and become lost
Remove inedible objects which patient attempts to eat

likely to be pleasant and stimulating. Care must be taken, however, to take the patients' perspective. There is a danger that in trying to make the surroundings stimulating they become confusing. The Domus philosophy of residential care is one recent attempt to improve the quality of those in long-term residential care (Lindsay *et al*, 1995). It is based on four assumptions:

- (a) That the residence (domus) is the person's home for life.
- (b) That the needs of the staff are as important as those of the residents.
- (c) That the domus should aim to correct the avoidable consequences of dementia and accommodate those that are unavoidable.
- (d) That the residents' individual psychological and emotional needs may take precedence over the physical aspects of their care.

Carers

Those intimately concerned with looking after people with dementia need two kinds of support: practical and emotional (see Chapter 18 for a fuller account).

Practical support

Financial

Many carers are not receiving all the financial support to which they are entitled. It is important to ensure that they are properly informed and helped with making financial claims.

Respite

Many carers want to continue to look after the person with dementia, but their ability to cope is undermined by the lack of any respite. Day care can allow carers to carry out necessary tasks, such as shopping. It may enable them to continue in paid work with both financial and social advantages, and it can give them some much needed time to enjoy themselves. 'Holiday admissions' in which the person with dementia is admitted for residential or hospital care for several days at a time, are another way in which carers can be given time to recreate themselves. It is sometimes possible for a sitter to look after the patient for several hours, in their own home, either during the day or at night, in order to allow the principal carer some respite.

Tasks

Help with providing food (e.g. meals on wheels), cleaning, washing and dressing (e.g. a home help) can also relieve some of the burden from the principal carer.

Education

The importance of education for the carer must not be underestimated (Pollitt, 1994). This includes information about the disease, its prognosis and likely consequences. It may include training in carrying out a programme of behaviour modification and information about giving medication. It can include information about the various means of obtaining practical support.

Emotional support

It is important that the carer is also cared for. Opportunities are needed for carers to talk about the problems they are having, and about their feelings, including the negative feelings about the person with dementia. Carers' support groups as well as experienced counsellors (such as community psychiatric nurses) can be of great benefit.

One carer, whose wife had Alzheimer's disease, writing about his own experience (Reveley, 1988) offered these pieces of advice: do not hide the disease from those around you; take care of yourself; enlist help in all areas; and take calculated risks.

Professional carers such as nurses, residential home staff, doctors and social workers, also need support and care. A professional team needs to build into it a mechanism to enable such support to be given. Hospital-based professionals can help the staff of residential homes to think about and to achieve their goals (see Garland, 1991).

Primary health care

The early diagnosis of dementia is important, not only to exclude treatable conditions, but because it is often the trigger for health and community

Box 6.8 Support the supporters; care for the carers

Financial: ensure financial entitlements

Respite: day care, holiday admissions, day sitting service, night sitting service

Practical: meals on wheels, home help

Education: about disease process, about medication, about behaviour modification programme, about support services

Care: individual counselling (e.g. community psychiatric nurses), carers groups (e.g. through Alzheimer's Disease Society), family and friends

services. In particular, a person with dementia is entitled to an assessment of needs under the 1990 Community Care Act. GPs act as gatekeepers to specialist services, but there is evidence that they tend to underdiagnose dementia (Ilfe *et al*, 1991). All people over 75 should now be offered an annual check by their GP and this may improve detection. After referral, it is important that community health teams and hospital-based teams liaise with the primary health care team. It is easy for hospital doctors to forget that GPs provide the major medical support for most people with dementia.

The multi-disciplinary team

The management of people with dementia requires many different tasks to be undertaken. It is not usually appropriate for one person to carry out all of these tasks and effective teamwork is vital. Box 6.9 lists some of the professions who contribute to the team. For management to be effective, good and frequent communication between the team members is needed.

Care Programme Approach

The Care Programme Approach requires that all patients accepted by specialist mental health services must have a keyworker who is

Box 6.9 Professional groups and some of their roles

Doctors: evaluation of concurrent illness; prescription of medication; facilitating provision of hospital and community services

Nurses: general care of in-patients and nursing home residents; carrying out behaviour modification regimes; education and counselling of relatives; coordination of community services

Clinical psychologists: initiating behaviour modification programmes, offering advice and support to staff in a caring role

Social workers: facilitating provision of local authority services such as residential care, respite care, home care; counselling of carers

Occupational therapists: design of environment; education of carers; identification of strengths and abilities of patient

responsible for making sure that their health and social needs are fully assessed. The keyworker is responsible for a care plan that is negotiated with the patient and their carers. Depending upon the local services, many people with dementia will be assessed by the old age psychiatric services, management suggestions made, and their care discharged back to their GP. Other patients will be followed up by the community team and require regular Care Programme Approach reviews.

Problem-orientated approach

The main steps in a problem-oriented approach to management need to be planned, if possible, with the whole team. Involve the patient, carers and the primary health care team in these processes as far as is possible. The steps are summarised in Box 6.10.

Conclusion

The management of dementia is sometimes thought to be an unrewarding area, of little intellectual interest. This is far from the case. Certainly there are no cures for the disease. For this reason, management requires the ability to think widely and imaginatively. This chapter has emphasised a structured approach to management. Of equal importance is attitude. Above all, management must be centred on respect for the individual.

Box 6.10 Steps taken in a problem-oriented approach to the management of dementia

Identify problems which might need addressing
Identify strengths of patient and the support system
Establish priorities for problems list
Set clear goals for management – these should be realistic
For each aspect of management decide who should be involved
Ensure patient and carers are well informed of plans
Set time for review
Carry out review: assess effectiveness of management plan and reassess problems and priorities

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