Chapter 6
Supporting Diagnosis and Treatment

6.1 Support at the Time of Diagnosis

We have deliberately started this chapter with the above quote from a ‘Person with dementia’, who has written the foreword for an authoritative book, Timely Psychological Interventions in Dementia Care [1], written and edited by two acclaimed European dementia specialists.

Doctors are generally well trained in diagnosing and treating diseases, but they are not always trained in how to deliver them properly. People with suspected dementia and their families experience a variety of emotions, worries and concerns at the time of diagnosis and afterward. They need information about their condition, including sensitive discussion about prognosis and limitations of drug treatment. People with dementia need to understand how their cognitive problems affect daily life, and how simple strategies can minimise the impact of these problems and improve their quality of life. People with dementia have to cope with the loss of independence and competence. Support and encouragement are needed to enable them focus on things they can still enjoy and derive a sense of achievement.

“As a person with dementia my social health is very important to my daily life. When I was diagnosed social health was never discussed with me. I was much more aware of social disengagement as sadly nobody within the health sector explained to me, I could carry on with my daily life and engagement with my community. I was grieving for life I would never have; I was not offered any post diagnostic support due to my age. I forgot I had rights and should be treated like everyone else and be fully integrated into my community as an equal citizen.”

Helen Rochford-Brennan [1] (Chairperson of the European Working Group of People with Dementia)
Dialogues and conversations with people with dementia regarding these issues are termed ‘psychosocial intervention’.

In early dementia the principle of psychosocial intervention applies to diagnostic consultation, confidentiality, gaining consent to speak with family members, organising physical investigations, disclosing the diagnosis, starting treatment with drugs, future planning, collaborative care, and more complex decisions such as who should take responsibility when the person with dementia loses the mental capacity to manage property or driving related decisions. Most people with early dementia retain capacity to make decisions in most areas, but families, friends as well as treating physicians often assume otherwise and may sometimes undermine their autonomy. The key to successful psychosocial interventions is that they are individualised to the person and their family tailored to their changing needs.

Historically, mental health services have been vulnerable across the world. In 2008, the Royal College of Psychiatrists launched a 3-year *Fair Deal for Mental Health* [2] campaign to tackle the inequalities faced by people with mental health problems. The College also made a commitment to ensuring that training for psychiatrists promotes the ‘Recovery Approach’. National guidelines emphasised the universal applicability of the recovery values for anyone of any age who has a significant mental health problem. Yet there was little thinking as to whether the recovery approach is applicable to dementia care. Jha et al. [3] in Hertfordshire, UK spotted the striking similarities between a recovery-oriented approach and person-centred care. Through a randomised controlled trial, they have demonstrated that older people’s wellbeing and autonomy can be improved by adopting an individualised recovery-oriented approach at routine memory clinics.

The aim of a person-centred recovery approach is to inform and empower the person with dementia and their family to be able to live well with the diagnosis of dementia. This can be achieved by targeting specific goals (established with the person and with their relatives) that can have a concrete impact on people’s daily life. Jha et al. have also provided a Mini Wellbeing State Examination (MWeSE) scale [3] specifically for this purpose. We believe that general physician in the developing world can be supported to provide person centred dementia care.

### 6.2 Disclosure of Diagnosis

Research indicates that patients generally would like to know the diagnosis of dementia [4]. While withholding of diagnosis is distressing for some patients, uncertain and late diagnosis are also unhelpful. The experience of diagnosis disclosure can be distressing for the patient, their family, and also for the doctor. It’s like breaking bad news. The person may feel a sense of loss, of stigmatism as well as of hopelessness as a result.
The patient and their family may require time to discuss the diagnosis and its implications. Delivering diagnosis of Alzheimer’s disease is a process, not an event. There is a great deal of information to be imparted and the implications of this thought through, and this takes time. The disclosure of diagnosis of dementia should be conducted at least in two interviews, because patients and family may not understand and retain information about the diagnosis after the first interview.

The ‘best practice’ guidelines for dementia disclosure include preparing for disclosure, integrating family members, exploring the patient’s perspective, disclosing the diagnosis, responding to patient reactions, focusing on quality of life and well-being, planning for the future, and communicating all of these sensitively and effectively. As non-specialist doctors you may not have expertise and time to offer that level of care, but you should try to provide alternative sources of information and support. The patient and the family may have the following questions to ask:

*Is there any cure?*
*How long have I got?*
*What can be done?*
*Is it hereditary?*
*Can I still drive?*
*Will vitamins/crosswords/exercise/diet help?*
*What about this alternative treatment I’ve found on the internet?*

None of these questions is easy to answer, but you should try to respond honestly and sympathetically. The skills required of professionals in diagnostic disclosure are similar to those used in other serious illnesses such as cancer. A patient-led discussion is preferable with adjustment and compensation for the degree of cognitive impairment and the patients educational and cultural background. Family carers may sometimes attempt to steer their relatives away from diagnostic discussion and it is important to consider whether discussion of the diagnosis should be carried out jointly with a family member or alone with the patient. Following discussion of diagnosis patients should be helped to use the information positively. While
discussing treatment, a collaborative approach of decision-making (also known as shared decision making) should be adopted. Helping people identify their values is thought to assist them in thinking about, and making, health care choices.

Family carers need to be informed of diagnosis and what to expect in the future. They need to be informed about what services and interventions can help. Sometimes there are problems for carers in balancing their own personal needs with those of the patient. Further difficulties arise where there are pre-existing ambivalent relationships, current ambivalence, and the presence of paranoia (for example leading to accusations or misidentification of the carer).

Box 6.1 provides the SPIKES [5] protocol for delivering a diagnosis of Alzheimer’s dementia, based on the principles of breaking bad news. SPIKES is an acronym for presenting distressing information in an organised manner to patients and families. The SPIKES protocol provides a six-step framework for difficult discussion:

- Step 1: Setting up the interview
- Step 2: Assessing the patient’s Perception
- Step 3: Inviting the patient for further information
- Step 4: Giving Knowledge and information to the patient
- Step 5: Addressing the patient’s Emotions with Empathic responses
- Step 6: Strategy and Summary

Box 6.1 SPIKES Six-Step Protocol for Delivering Alzheimer’s Diagnosis

Mr. Thapa is a 67 old man being seen by a physician at a Kathmandu clinic along with his wife. At the initial assessment, he was found overweight and he was found drinking excessive alcohol. On cognitive testing, he had scored low at 10/30 on RUDAS scale (cut off score 22). Today, he has come to the clinic to review the findings of the initial assessment with his doctor. He was anxious and worried. Dr. Mishra has been his doctor for a number of years, and he knew that the diagnosis of Alzheimer’s will be difficult for him to hear. So, Dr. Mishra sets the stage for this difficult encounter, using SPIKE protocol (acronym for Setting, Perception, Invitation, Knowledge, Empathy and Strategy):

1. **Setting**: Before meeting with the patient, Dr. Mishra prepares the setting, the first step of the SPIKES strategy. In preparation of the meeting it is important to review the patient’s medical history and facts about the diagnosis prior to his visit. It is important to make sure that the meeting is in a private and a quiet location with enough sitting for everyone present, and set aside enough time for discussion, and minimise distraction, like turning off your mobile phone. Remember to remain calm and attentive.

2. **Perception**: It means, before you tell, ask what the patient knows or expects. In particular how serious he/she thinks the illness is, and/or how much it will affect the future. Verbal (words the patient uses to convey
emotion) and non-verbal (body posture, hand movements) indicate anxiety possibly under a brave front.

Dr. Mishra: “Tell me how things have been going since we last met”.

3. **Invitation:** Before you tell, assess how much information the person wants to receive. The real issue is not “Do you want to know?” but “at what level do you want to know?”

Dr. Mishra: “Let me first explain the result of the memory test, before I tell you what the diagnosis might be”. Once the patient accepts the invitation to discuss the results, move to the next step of the SPIKES process.

4. **Knowledge:** In this step, the information is explained.

Dr. Mishra: “Your blood tests did not reveal any findings which were new or of concern. Unfortunately, your memory and functioning tests brought some concerns.—Dr Mishra stops for a pause. The patient asks, “What do you mean?” Dr. Mishra: “Let me summarise. Your long-term memory is quite good. However, your short-term memory is not so good. That means, remembering words, and difficulty with complex tasks, such as managing money. I wish I had better news Mr and Mrs Thapa. Unfortunately, when we take the results of all the tests together, this suggests a diagnosis of an early stage Alzheimer’s disease. That is a most common form of dementia.”

Patient: “Alzheimer’s! At my age! How can that be?”

Mrs. Thapa: “Are you sure? Could it be something else? Maybe medicine he is on?”

Dr. Mishra: “Well, I looked at everything. The blood tests, the medication he is on to make sure, I was not missing anything causing your symptoms. Alzheimer’s disease is the most likely diagnosis.” The diagnosis is conveyed simply and directly, without any medical jargon. And with empathy. Information is conveyed in small amounts for the patient to process.

5. **Emotion & Empathy:** After reporting the difficult news, address the patient’s emotions and show empathy.

Patient: “My grandmother might have had something like this. I am afraid of getting this”.

Dr. Mishra: “I know it is scary, but I am glad you came in and agreed to go through the assessment and examination. The early we know about dementia, the more time we have to plan ahead.”

Mrs Thapa: “So there is a medicine to cure him.” Dr Mishra: “No, unfortunately, there is no cure for Alzheimer’s at this moment. There are some medications that can slow down how quickly the illness progresses. The purpose of this medication is to help preserve Mr Thapa’s memory as much it is possible and for as long as we can.” Mrs Thapa: “So, what do we do? Start the medication?”
It is important for the patient to realise that “just because they have got a failing memory does not mean they are failing”. Patients and families need adequate time to discuss the diagnosis and its implications, not only because of the potential emotional impact of the diagnosis, but also because the majority of patients and a significant minority of relatives do not retain information about the diagnosis after the first disclosure. Like some GPs in the UK, you may consider seeing patients with suspected dementia towards the end of your clinic for a longer unhurried period of time.

### 6.3 Frequently Asked Questions After Diagnosis

Disclosure of diagnosis presents an opportunity to provide patients and families with information about their condition, treatment and sensitive discussion about prognosis. They need to understand how their cognitive problems affect daily life and consider simple strategies to minimise the impact of these problems. They may need to discuss the implication of the diagnosis on driving and related issues. Travel and insurance issues may be discussed along with finance and benefit entitlement. This section discusses some of the frequently asked questions and possible answers and explanations (adapted from case examples from Moniz-Cook et al) [6].

#### 6.3.1 Question 1: Would I End Up in a Nursing Home?

Mrs Brown went to her general physician to discuss her new diagnosis given by the neurologist. She was a 64-year-old store manager in a local grocery shop. She has been complaining problems with her memory and managing the computer system and sales counter. Recently, she experienced difficulty
organising 80th birthday party for her husband. She was anxious she might make mistakes at work and so had taken sick leave.

Mrs Brown initially believed she might have a brain tumour although the neurological investigations quickly ruled that out. However, when she received the diagnosis of Alzheimer’s disease from the neurologist, she described herself as ‘only half prepared’. Her first action was to resign from her job. She wanted to know her diagnosis but felt she had been told in an insensitive way which did not encourage information seeking or offer any hope or reassurance. She had not told either of her daughters or any other friends and family about the diagnosis and was avoiding social contact whenever possible. She had been offered a trial of the anti-dementia drug donepezil but was undecided about this as she felt there was no point. She described an inability to enjoy anything, lack of motivation and a feeling of numbness. She made a new will and drew a power of attorney shortly after hearing the diagnosis.

She had gone to her own physician to discuss the impact of the diagnosis of Alzheimer’s disease. She was feeling hopeless and very worried about her future. She experienced frequent intrusive thoughts and imagery of being in a nursing home, highly distressed, and in an advanced state of dementia. She also described feeling of anger and ‘why me?’ she felt distressed whenever she thought about the diagnosis or was reminded of it in any way.

Her own doctor had special interest in dementia care and listened to her in a way she felt understood. She was helped to understand about her condition and in doing so realised that it could be many years before she reached that level of disability. She had some misinformation stemming from past experience about her husband’s memory problems. She felt reassured and agreed to take donepezil as a useful part of her overall coping strategy.

It was suggested that sharing the diagnosis with other family members and close friends could be a good thing, as trying to cover up cognitive problems was exhausting and led to social withdrawal. She was encouraged to pace her activities and not cram too much into one day, to carry out one task at a time and to spend time planning her activities. She was asked to continue activities she knew she could manage, particularly if they were sources of enjoyment. She also recorded activities she was finding difficult and identified what help she would need were she to continue working at the grocery shop. Her daughters were also present at the consultation.

Mrs Brown was gradually able to accept the diagnosis and had more control over her wellbeing. Few months later, she still feared for the future, but these fears were more realistic and less overwhelming. She responded well to the donepezil and intended to continue with it for as long as it proved useful.

Comments: being open with people about diagnosis presents a real opportunity for clinicians. Encouraging patients with dementia share their feelings and asking questions allow us to think and respond more appropriately to the challenges of
dementia care. You do not need to be a trained counsellor or a clinical psychologist to offer post diagnostic support. Being sensitive and open are enough to win the trust of the patient and their family.

6.3.2 Question 2: What Are TIAs/Mini Strokes?

Mrs Thakur was a 78-year old housewife who came to the doctor because her husband was convinced that she had dementia and wanted the prescription of Aricept (donepezil) that might help her. Mrs Thakur herself was not interested in any drugs—‘let alone drugs for the mind’. She felt that her memory ‘was fine’. Mrs and Mr Thakur had used the internet to find out about dementia before attending the clinic. They both agreed that in the past 3 months she had become somewhat hesitant and lacking in confidence, particularly with activities in the home. Mr Thakur felt he now had to do more to assist with preparation of meals and some household tasks. Mrs Thakur had also recently decided to stop driving and discontinue her insurance for their joint car. At the diagnostic assessment, the doctor had discussed the diagnosis of vascular dementia. Mr Thakur remained keen that his wife was offered an anti-dementia drug. Mrs Thakur did not want to take any drug, and having outlined her day-to-day concerns, she requested a second opinion from a renowned neurologist in the nearby city to be sure whether her brain was functioning alright.

The neurologist examined Mrs Thakur and organised a CT scan of her brain. She was told that Transient Ischaemic attacks (TIAs) or ‘Mini Strokes’ are the second most common cause of memory difficulties in people over 65. They occur when a part of the brain is temporarily deprived of its blood supply, which carries oxygen to the brain. They may occur suddenly and last for quite short periods—between 5 and 30 min and much less in the case of a TIA; others may be aware of ‘strange sensations’; and in other cases temporary problems such as double vision, numbness, weakness or tingling in an arm, leg, hand or foot and dizziness are reported. Mostly people feel they have ‘recovered’ from these episodes after a period of time. Mini strokes can affect any part of the brain—in Mrs Thakur’s case they had affected functioning towards the back of her brain. This means that most of the brain was working fairly normally for her age and some parts of the brain may have had taken the function of parts where complete recovery from the mini stroke had not occurred.
6.3.3 Question 3: How Can I Stop Things from Getting Worse?

Mrs Thakur was advised by the doctor to start taking aspirin to thin her blood and thus reduce the likelihood of a further mini stroke. Having high blood pressure can make things worse but her doctor had already prescribed medication for it. She was advised to come to the clinic regularly to monitor her blood pressure at least once a year for blood tests to check that she had not developed new conditions such as pneumonia, diabetes and so on. She was also advised to keep her alcohol intake to a minimum as excessive alcohol, like fat and salt, raise blood pressure. Since she was hypertensive, she was also advised to slightly reduce her caffeine (coffee and tea) intake and eat a well-balanced diet, which is low in fat and salt. Since she was not taking any form of exercise, she was advised to go for a 30-min walk every day.

6.3.4 Question 4: Why Do I Have Trouble ‘Getting Going’?

Mrs Thakur sometimes had difficulty putting her thoughts into action. Although she knew exactly how to do something and could describe it to others, she had difficulty carrying out the action or activity. She had difficulty starting an activity, i.e. her ‘start motor’ was slow. Sometimes this can make other people think that she was ‘hesitant’ or had lost confidence or was being slow, but she was advised to recognise that was not the case. If this occurs, she was told to ask her husband to physically prompt her to get going on a task. Once she gets going, she won’t have too much trouble continuing with what she wanted to do.

6.3.5 Question 5: Should I Stop My Social Activities?

It is very important to encourage patients diagnosed with dementia to continue with whatever social activities/hobbies they were doing even though they might be embarrassed at the apparent ‘mistakes’ they make. Activities like weekly meeting with friends, contact with grandchildren, provide important mental stimulation. They should adopt the policy of ‘use it or lose it’ and do these activities with people they trust—who will overlook the patients’ occasional mistakes and encourage them to get going.
### 6.3.6 Why Has My Mother Become So ‘Lazy’?

A 69-year-old widow has been living with her daughter Kerry for last 20 years. She reported to her doctor that she was concerned about her mother’s declining memory. Kerry did not feel that her mother had memory problems but that she had become increasingly ‘lazy’ and had lost interest in the house. Kerry felt that she had to constantly ‘nag’ her mother to do things. Both agreed that this had led to increasing tension in the household. When the doctor performed RUDAS cognitive test, the patient had shown signs of ‘abnormal executive’ functions, what psychologists refer to as ‘Dysexecutive Syndrome’. This syndrome is caused by cognitive deficits in the frontal lobe of the brain causing difficulties with motivation and task initiation. Kerry was able to understand that her mother was not ‘lazy’; she was showing signs of early Alzheimer’s disease which had affected the front of the brain rather than the temporal lobe which causes memory problems.

### 6.3.7 Why Does My Husband Not Listen to Me and Avoid Me?

Reduced ability to communicate has an impact on relationships of patients with relatives and treating clinicians. Communication can be affected early on in dementia with receptive or expressive dysphasia/aphasia. This may come across as the patient not listening or avoiding conversation. Specific attention to compensating for functional language loss is relevant to everyone involved. Steps taken will include attempting to use a calm and organized environment which is free of distractions; sensory input, both hearing and vision, should be maximized and clear initiation of conversation may be established by use of face-to-face contact or touch; the matters to be discussed should be simplified and presented one at a time. Orientation to the topic of conversation may help, as well as written prompts and reminders. Gesture may remain intact and may be helpful. The person, or those who know them, can help determine in which way they can assist if they get stuck. For example, does sentence completion help or make things worse? Reassurance and support for frustration needs to be given when this occurs. Dementia contributes to loss of the second language and reversion to mother tongue may confound accuracy of diagnosis. For instance, a Nepalese doctor may find that a patient coming from outside Kathmandu has forgotten to speak in the Nepalese language and reverted back to her native Maithili language. In addition to educational and cultural factors, incorrect assumptions about literacy and misunderstanding of certain concepts can result in overestimating cognitive loss while missing other functional reasons for deteriora-
Clinical Management of Early Dementia

The concept of treatable and non-treatable dementias is no longer relevant; all dementias are treatable, albeit not necessarily curable. Disease-modifying therapies are still not available. Cholinesterase inhibitors provide modest stabilisation of changes to cognition and ADLs associated with the disease. They do not reverse or stop the degenerative processes. One of the most effective therapies for AD is proactively managing underlying vascular risk factors.

The core principles of management of early dementia include improving cognition, maximising independence, maintaining function, and planning for the future. A common point of concern or interest between patient and carer needs to be established with flexibility and sensitivity. Bridges may be built through attention on a physical health focus for some patients while for the carers addressing behavioural and psychological symptoms, such as agitation and sleep disturbances, may be the priority.

Drug Treatments

Currently, there is no cure for Alzheimer’s disease, but there are medicines to help improve symptoms and prevent deterioration. The only approved drug treatments in many countries for cognitive symptoms of dementia are for Alzheimer’s disease, dementia with Lewy bodies, or Parkinson’s disease dementia. They target biochemical abnormalities as a consequence of neuronal loss, but do not modify the underlying neuropathology or its progression.

Cholinesterase inhibitors are expected to partly restore the deficit in acetylcholine arising from loss of neurones in the nucleus basalis of Meynert (see Box 6.2), and in the central septal area, projecting to cortical regions. The search for abnormalities in brain neurotransmitter system in Alzheimer’s disease was inspired by the successful use of L-dopa in treating dopamine deficiency in Parkinson’s disease.
These drugs have similar efficacy in improving symptoms of cognition, function and behaviour. They may also delay the onset of the behavioural and psychological symptoms found in more advanced stages of dementia, reduce caregiver burden, and delay care home placement. As there is no means of determining who will, or will not, respond to these anti-dementia drugs, we usually prescribe for a 3-month trial of efficacy with gradual increase of the dose. Side effects tend to appear mostly during the initial, titration phase of treatment. Adverse events tend to be short-lived. A great majority of patients experience only minimal side effects, the number of patients discontinuing treatment because of adverse events is fewer in clinical practice than in the clinical trials. However, caution should be exercised in patients with cardiac conduction defects or significant bradycardia.
Three cholinesterase inhibitors, donepezil, rivastigmine, and galantamine, are in routine use.

6.6.1 Donepezil

Donepezil was licenced in Europe in 1997 as the first available treatment for mild to moderately severe AD. **Donepezil** is available as tablet or orodispersible tablet; **rivastigmine** is available as a transdermal patch or capsule or liquid, and **galantamine** as a capsule.

One of the early pivotal studies evaluated the use of donepezil at either 5 mg or 10 mg against placebo, over a 6-month period, in 473 patients. A quarter of patients taking the higher, 10 mg, dose improved by gaining 6–12 months’ gain in cognitive function compared with their baseline level. Further studies have found the efficacy of donepezil up to 240 weeks.

Although a large majority of patients respond well to donepezil group of drugs, not all of them show similar improvement. There is no means of determining who will, or will not, respond to such treatment, 3–6 months treatment trial with an AChE is recommended.

The beneficial cognitive effects of higher dose of donepezil are mirrored by the adverse event profile, especially gastrointestinal side effects. Fortunately, these side effects are usually short-lived, and majority are free of adverse effects, or experience only minimal symptoms.

Caution should be exercised in those patients with conduction defects as these drugs may cause severe **bradycardia**. Therefore, donepezil group of drugs is contraindicated in heart block or pulse rate below 50/min.
6.6.2 Memantine

Memantine is a non-competitive modulator of the N-methyl-D-aspartate receptor and normalises glutamatergic neurotransmission. It prevents excitatory aminoacid neurotoxicity, and is the only drug licenced for severe Alzheimer’s disease. It is usually given up to a dose of 20 mg per day.

A combination of memantine and cholinesterase inhibitor has recently been recommended for moderate-to-severe AD.

6.6.3 Souvenaid

Souvenaid is a medical food product for oral consumption formulated to meet nutritional requirements in Alzheimer’s disease. It comprises of several ingredients that are hypothesised to be useful as precursors and cofactors for the formation of neuronal membranes, and consumption of souvenaid increases their concentrations.

6.7 Herbal Cholinesterase Inhibitors

In addition to the cholinesterase inhibitors and memantine, researchers have studied herbal medications, huperzine and bacopa to treat cognitive symptoms of AD.

Huperzine [7], is a Chinese herb extract, which may have some beneficial effects on patients with AD.

Similarly, Mishra et al. [8] have recently reported the preliminary findings of positive response of Brahma (Bacopa monnieri Linn) on patients with dementia. Brahma is an over the counter widely available Ayurvedic herb traditionally used in India as a memory-enhancer.

However, the findings of these studies should be interpreted with caution due to the preliminary nature of the reported studies.

6.8 Immunotherapy with Aducanumab

In October 2019, the pharmaceutical company, Biogen announced that the anti-amyloid antibody aducanumab has shown modest but significant efficacy in a phase 3 trial, providing important validation of amyloid A β hypothesis of Alzheimer’s disease. Aducanumab is a human monoclonal antibody that selectively binds to amyloid β fibrils and soluble oligomers.
Recent research has focused on therapies targeting amyloid precursor protein metabolism, $\text{A} \beta_{1-42}$ deposition or clearance. For example, inhibition of the enzymes $\beta$-secretase, which is responsible for the metabolism of amyloid precursor protein.

Two types of immunotherapies are under investigation—injecting amyloid to create host immunity (active immunization) and injecting intravenous immunoglobulin antibodies to clear amyloid from the brain (passive immunization). Aducanumab is an example of passive immunization, by binding with soluble $\text{A}\beta$ and promoting its removal from the brain through the blood stream.

### 6.9 Summary Drug Treatment and the Future

Cholinesterase inhibitors (donepezil, rivastigmine, and galantamine) have small but clinically important effect on cognition and function (of all severities of) in Alzheimer’s disease but have side effects. Memantine has a smaller effect on cognition, but useful for people who cannot tolerate the side effects of cholinesterase inhibitors. Disease-modifying therapies, including passive immunization, are under investigation.

### 6.10 Other Cognitive Interventions

Cognitive stimulation therapy [9] has recently been found to improve cognition. It is a group-based therapy led by a trained coordinator incorporating social activity, reminiscence, and simple cognitive exercises (Box 6.3).

**Box 6.3 Cognitive Stimulation Therapy (CST)**

The aim of CST is to actively mentally stimulate participants through cognitive activities and reminiscence, multisensory stimulation, and group social contact. Each session is led by a facilitator. The standard CST model is a group intervention of 14 themed sessions, each lasting approximately 45 min and held twice per week. This standard programme has been manualised and can be potentially administered by anyone working with people with dementia and held in care homes, hospitals, or day centres.

The programme includes:

- A non-cognitive warm-up activity (e.g. soft ball game and song)
- Elements of really orientation including a board displaying personal and orientation information

Sessions then focus on different themes, including childhood, food, current affairs, use of money, faces, scenes, and quizzes or word games.
6.11 Specific Management Issues

6.11.1 Planning for the Future

At an early stage of Alzheimer’s, patients usually still have the capacity to make decisions about their care in the future and should be actively involved in decision-making. They may be aware that they are beginning to find it difficult to manage their financial affairs, perhaps forgetting how much money they have withdrawn from the bank. It is important to discuss whom they would like to nominate for managing their financial affairs when they are no longer able. They may become vulnerable to financial exploitation. They may also wish to legally appoint someone to make decisions about their future health and social care. Using the relevant laws and regulations of the country of residence, people with early dementia may be able to make advance decisions about life-sustaining treatment. These decisions need to be made after considerable thought and discussions between patients and family members.

6.11.2 Maximising Communication

Communication can be affected early on in dementia with receptive or expressive aphasia. The pragmatics of language (turn-taking and topic management) may also be affected. Reduced ability to communicate has an impact on relationships as well as on the wellbeing of the patient. Family members should be encouraged to use clear, simple conversation, to reduce high emotional expression, use memory aids, and to be non-judgemental.

Specific attention to compensating for functional language loss is relevant to everyone involved. Steps taken will involve:

- Attempting to use a calm and organized environment which is free of distractions
- Sensory input, both hearing and vision, should be maximized and clear initiation of conversation may be established by use of face-to-face contact or touch
- The matters to be discussed should be simplified and presented one idea at a time
- Orientation to the topic of conversation may help, as well as written prompts and reminders
- Gestures may remain intact and may be helpful

The person, or those who know him or her well, can help determine in which way they can be assisted with if they get stuck. For example, does sentence completion help or make things worse. Reassurance and support for frustration needs to be given when this occurs.
Validation therapy is an approach to communication which acknowledges and supports the feelings of a disorientated person in whatever reality they experience rather than grounding them in the here and now.

6.11.3 Maintaining Function Through Pleasurable Activities

Loss of opportunities to engage in pleasurable and rewarding activities is important both for the individual and for carers since such losses contribute to a vicious cycle of reduced communication, lower mood, less participation in any activity, and increased dependence on others.

As the disease progresses there needs to be an on-going process of finding activities within the person’s ability, and structured approach can be helpful. Carers who are aware of appropriate and enjoyable activities enjoy an improved sense of satisfaction and reduced feelings of burden.

There may also be a preventive role; for example, at day centres or social clubs the combination of structured exercises and conversation may reduce deterioration in mobility.

6.11.4 Caring the Carers

It is worth keeping in the mind that the diagnosis of dementia also has important implications for primary carers—the person closest to the patient (usually the spouse), who suddenly finds themselves wearing the label ‘carer or caregiver’ and often need support themselves. Thus, dementia care is not simply a reaction to a crisis; it also involves enabling caregivers to continue caring for an indefinite and often uncertain periods of time. They require psychosocial support in forms of active listening and emotional support.

Physicians may want to do something to help families but may not know what to do. There is some evidence that providing knowledge and opportunity for the families to access the right help for a particular problem during problem through solving consultations may be effective. Goals may be broken down into small clear and achievable entities. For example, physicians may be able to assist the carer to get a good night’s sleep by prescribing a hypnotic for them. Research suggests that even when only small and limited goals are achieved, an unbearable situation may change into one where there is still some hope and pleasure in life. Family carers can be empowered to realise their wishes and avoid things that they do not wish to do. Through this process of mobilising caregivers’ strengths, there is a possibility that exhaustion or burnout may be prevented.
The provision of both practical and emotional support to patients and their families is critical at all stages of their journey. Caring for persons with advanced dementia is extremely demanding. Without support, caregivers feel exhausted, isolated, and unable to cope. Since specialist dementia care services are not available in developing countries, onus of care falls on the immediate family and relatives. As the local physicians, you may be able to mobilise local community resources to set up day care, sitting services, along with transport and shopping for the affected families.

6.11.5 Management of Neuropsychiatric Symptoms

Neuropsychiatric symptoms in dementia are common; they generally increase with severity of dementia and affect nearly everyone with dementia at some point during their illness. Although many different symptoms exist, they often co-occur in clusters—affective, psychotic, and other symptom clusters. They also vary with the underlying cause of dementia, with visual hallucinations being more common in Lewy body dementia.

Distressing problems arising with progression of dementia include sleep disturbance, behavioural problems, such as agitation, wandering, swallowing difficulties, incontinence, and immobility. Behavioural and psychological symptoms (BPSD) are summarised in Table 6.1:

The overlap between these symptoms highlights the need for careful assessment of symptoms and potential causes, advocated by the DICE (Box 6.4).

Box 6.4 DICE Approach to Manage BPSD
- Describe the problem
- Investigate the cause
- Create a plan
- Evaluate the effectiveness of it

6.11.5.1 Depression

People with early dementia may have comorbid depressive illness. The prevalence of depression in dementia is around 20%. They exhibit typical symptoms of

| Behavioural symptoms | Psychological symptoms |
|----------------------|------------------------|
| Night-time disturbances | Anxiety |
| Wandering | Hallucinations |
| Agitation | Delusions |
| Aggression | Uncontrollable emotional outbursts |
depression including anhedonia (lack of pleasure in life), amotivation, tearfulness, insomnia, and lack of appetite.

As effective treatment often improves cognition and function, a new diagnosis of dementia should usually be suspended until after the depressive illness is successfully treated.

Treatment of depression in early dementia is likely to enhance psychological wellbeing, physical function (through improved motivation, and general quality of life. Older patients often tolerate tricyclic antidepressants with fewer anticholinergic side effects (e.g. lofepramine) or an SSRI. Possible side effects include gastrointestinal bleeding, hyponatraemia, and falls and fractures.

6.11.5.2 Agitation

Agitation constitutes a range of behaviours, including restlessness, pacing, repetitive vocalisations, and verbal and physical aggression. The behaviours are often accompanied by a feeling of inner tension, although this tension is more difficult to detect in people with advanced dementia.

The cause of agitative symptoms varies. They might be a communication of physical or psychological distress, a misinterpretation of threat, or result from delusions or hallucinations in a person with dementing disease, which reduces their ability to communicate, satisfy, or even know their needs. Agitated behaviours are more common in moderate or severe dementia, especially in care homes, because the symptoms are associated with the breakdown of care in domestic settings leading to care home admission. This makes caring for people with dementia more difficult and time consuming.

Management of Agitation

Management of agitation in dementia should start with asking the person what is wrong. If they cannot articulate or communicate, the following causes of agitation should be considered and addressed, whether the person is feeling:

- Frightened
- Hungry
- Thirsty
- Hot or cold
- In pain

Overstimulation or complex environments might also exacerbate agitation. Interventions to manage agitation and aggression primarily depends on improving
caregivers’ attitude and communication skills. Caregivers need to have time and patience to identify and respond to the person’s wishes in the spirit of so called ‘person-centred care’.

### 6.12 Psychosocial Interventions

From a social perspective, dementia can be viewed as one of the ways in which an individual’s personal and social capacities may change for a variety of reasons.

A psychosocial approach should:

- Focus on retaining abilities and avoiding negative stereotyping;
- Provide activities that promote autonomy;
- Normalise or personalise activity support by basing this on knowledge of patients’ past pleasure, values and interests; and
- Provide a gatekeeping function to prevent others—such as families and professionals—from undermining access to interventions by the person with dementia,

The management protocol of the WHO mhGAP intervention Guide recommends the use of psychosocial interventions comprising of the following components:

1. Psychoeducation
2. Management of behavioural and psychological symptoms
3. Promotion of functioning in activities of daily living and community life and
4. Interventions to improve cognitive functioning

#### 6.12.1 Follow-Up

It is important to remember that dementia is a progressive and degenerative disorder. There will be deterioration in the person’s cognitive, emotional, behavioural and physical functioning along with their ability to carry out the activities of daily living. People diagnosed with AD should be reviewed at least every 3 months.

- If not on medications, initiate pharmacological intervention, if appropriate.
- If on medication, review adherence, side effects and dosing. Adjust or consider alternative medication as appropriate.
- In addition, review psychosocial interventions and evaluate for medical problems.
- Assess safety risks and offer appropriate behaviour modification if disease has progressed (e.g. limit driving, cooking, etc.)
- Assess for new BPSD, symptoms of depression and risk of self-harm.
- Continue assessing carer’s needs and provide psychosocial support to both patients and carers throughout their dementia journey, including end of life care.
References

1. Rochford-Brennan H. Foreword. In: Manthorpe J, Moniz-Cook E, editors. Timely psychosocial interventions in dementia care: evidence-based practice. London: Jessica Kingsley Publishers; 2020.
2. Deahl MP. The Fair Deal campaign: a call to arms. Br J Psychiatry. 2010;197(1):1–2.
3. Jha A, Jan F, Gale T, et al. Effectiveness of a recovery-orientated psychiatric intervention package on the wellbeing of people with early dementia: a preliminary trial. Int J Geriatr Psychiatry. 2013;28(6):589–96.
4. Jha A, Tabet N, Orrell M. To tell or not to tell—comparison of older patients’ reaction to their diagnosis of dementia and depression. Int J Geriatr Psychiatry. 2001;16(9):879–85.
5. Baile WF, Buckman R, Lenzi R, et al. SPIKES—a six-step protocol for delivering bad news: application to the patient with cancer. Oncologist. 2000;5:302–11.
6. Moniz-Cook E, Gibson G, Harrison J, et al. Timely psychosocial interventions in a memory clinic. In: Moniz-Cook E, Manthorpe J, editors. Early psychosocial interventions in dementia: evidence-based practice. London: Jessica Kingsley; 2009. p. 60–2.
7. Yang G, Wang Y, Tian J, et al. Huperzine A for Alzheimer’s disease: a systematic review and meta-analysis of randomized clinical trials. PLoS One. 2013;8(9):e74916.
8. Mishra M, et al. Brahmi (Bacopa monnieri Linn) in the treatment of dementias—a pilot study. Future Healthc J. 2019;6(Suppl 1):69.
9. Spector A, Thorgrimsen L, Woods B, et al. Efficacy of an evidence based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. Br J Psychiatry. 2003;183:248–54.