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19.1 Introduction

Owing to a global change in age demographic, dementia remains a major public health concern and a socioeconomic priority. In 2010, 35.6 million people were estimated to be living with dementia worldwide [1]. This number is expected to increase to 65.7 million by 2030 and 115.4 million by 2050 [1]. In the UK, there are currently around 700,000 people with dementia; this is estimated to rise to 1 million by 2020 and 1.7 million by 2050 [2]. The annual societal cost of dementia worldwide is estimated to be around US\$604 billion [3] and in the UK £20 billion [4]. Amongst chronic disease, dementia remains one of the most important contributors to dependence, disability and nursing home placement [5]. Increasing prevalence has driven government responses. In the UK this has included the National Dementia Strategy, which sets out a number of key national commitments in dementia care, emphasising on good-quality earlier diagnosis, easy access to care and focus on better quality research into dementia [6].

It is recognised that dementia in general is underdiagnosed and undertreated by primary care physicians [7]. This is probably a reflection on case complexity and time pressures associated with primary care. Research has shown that “watchful waiting” is adopted for people presenting with symptoms suspicious of cognitive impairment rather than immediate referral to specialist services [7, 8]. Although we should not underestimate the obstacles that primary care physicians face when dealing with these

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complex individuals, timely diagnosis remains key if we are to provide timely intervention and support to enable these patients to live well in the community.

19.2 Mild Cognitive Impairment

People with dementia may exhibit an early preclinical phase of cognitive impairment. Mild cognitive impairment (MCI) was introduced as a “clinical entity” over 20 years ago to represent a stage of cognitive impairment where the individual does not have any impairment of activities of daily living. However, MCI may or may not represent a transition to dementia. The annual conversion rate of MCI to dementia varies from 5 % to 10 % according to the definition of MCI used [9]. Although the incidence of dementia in MCI individuals is higher than the general population (4.4 %), it is the minority that progress to dementia in the MCI population [9].

MCI is felt to be a distinct entity from the cognitive changes that will occur with normal ageing. The concept of MCI provides an intermediate clinical diagnosis, often for watchful waiting, and may facilitate preventative interventions to delay cognitive loss. Various classifications/definitions exist [10]. A change in cognitive abilities is required for a diagnosis of MCI, and this information is usually obtained from either the person with suspected cognitive impairment or from their next of kin. There is no gold standard to specify which neuropsychological test to use to assess cognitive impairment.

19.3 Screening for Dementia

To help improve diagnostic rates, calls for dementia screening have been advocated. However the UK National Screen Committee (in 2003, updated in 2006, 2009) concluded that there is no evidence base to introduce a routine population-screening programme [11]; committees outside the UK (e.g. US Preventive Services Task Force) have also reached similar conclusions [12].

However in the UK, a Direct Enhanced Service (DES) to encourage and reward general practitioner (GP) practices to facilitate earlier, more timely diagnosis of patients with dementia has recently been introduced. DESs are additional services outside the normal scope of primary care services to address the needs of the local population commissioned by local health boards. The emphasis of the DES is to identify patients at higher clinical risk of dementia as well as working with their local specialist services to offer assessment, referral and early intervention services to ensure the dementia diagnosis is made as close to the patient’s home as possible [13].

19.3.1 Symptoms and Presentation

General practitioners (GPs) are well placed to recognise and diagnose symptoms of dementia. There may be a number of factors that may delay a diagnosis of dementia. Recognised difficulties encountered in primary care when diagnosing dementia

include atypical or non-specific presentations and the presence of co-morbid features [14]. For the patient and their families, there can be a misinterpretation or denial of their symptoms (for fear of stigmatisation) and also a fear of institutionalisation once a diagnosis has been made [15]. GPs are also impeded by a perceived lack of skills, knowledge and training with individuals having varying levels of experience [16, 17]. Individuals will have varying levels of experience in diagnosing and managing dementia, which can be supplemented by educational programmes tailored for primary care.

Dementia is a progressive, insidious and chronic disorder, and the initial clinical picture can be diverse ranging to what may be interpreted as normal ageing memory loss to difficulty in finding words or making decisions. The individual may present with a change in personality or mood with features similar to depression (see Sect. 19.3.3). Signs and symptoms may be subtle. They can present with memory problems, difficulties in communication and changes in behaviour and/or personality noticed by a concerned carer [8]. Suspicions tend to arise on a background of sudden changes of environment, e.g. hospitalisation, change in medications or the absence of his/her main carer [18]. There may also be subsequent problems in everyday tasks in work or at home [19]. This may be dependent on the individuals previous levels of education and baseline functioning.

19.3.2 Initial Assessment

Diagnosing dementia is still largely a clinical assessment [18] but is helped by increasingly accurate scanning techniques. Assessment of the patient in primary care requires careful history and examination, supplemented with a collateral history from their family and/or main carer(s) and brief cognitive assessment tests. The initial aim for the GP is to detect potentially reversible causes of cognitive impairment.

Discussion should be sensitively centred around any disturbance to daily living such as problems with finances, self-care, decision-making, missing appointments and behaviour that is new and not normally associated with the individual. The general practitioner, who may know the individual and family well, is in an ideal position to identify such problems. Assessment of past medical and educational history will also be important. Medication may also be an important factor; a review of the medication, the dosages and interactions between them is essential to ensure that they are not a trigger for cognitive impairment. This should also include over the counter and herbal remedies. An assessment of mood may also be relevant followed by a trial of antidepressants if “pseudodementia” is suspected.

19.3.3 Case Study 1: Memory Loss Following Bereavement

The daughter of an 86-year-old lady has requested a house call; she is present at this review of her mother. The lady lives alone and according to the daughter has been going “downhill” for around 6 months. She is refusing to look after herself properly and her daughter organised daily social care support in order to allow her to continue

to live in the community independently. Her memory is “not as good as it used to be”, and when questioned by her family, she is often unable to give an account of the previous days or weeks of events. The patient has a background of hypertension and non-insulin-dependent diabetes but is rarely seen at the practice except at annual reviews. She is well known in the community for having organised numerous charitable and social events in the past. On further questioning, the daughter is worried that her mother is developing dementia like her father who sadly passed away around 8 months ago. When questioning her mother, she reports that she has little interest in doing things she enjoys anymore, has felt down and “just wanted to be with her husband”. Her General Practitioner Assessment of Cognition (GPCOG) score was 5. Six months later, following bereavement counselling and a course of antidepressant medication, although not back to herself completely, she feels much better and the social care package has been reduced. Her repeated GPCOG score was now 9.

Collateral history from the family or carer(s) can clarify what the symptoms are as well as the timescale involved in relation to their baseline premorbid mental function. Although not commonly used, informant-based questionnaires such as “Ascertain Dementia 8 (AD8)” can be used to structure the consultation [20] and can be done either face to face or via a telephone consult.

Examination should also include any uncorrected audiovisual disturbances as well as nutritional status (as evidence of self-neglect) [21]. Examination should also assess for any signs of either new illness such as cardiorespiratory disease, anaemia, thyroid disorder or deterioration in existing comorbidities. These are typically responsible for precipitating and prolonging dementia. Although a full-neurological examination may not always be possible in primary care, some abnormalities in the pyramidal and extra-pyramidal pathways can be assessed for. Brisk reflexes and extensor plantar responses could indicate vascular dementia, whereas an expressionless face coupled with bradykinesia and cogwheel rigidity could indicate dementia with Lewy bodies [21].

The aim of initial investigations for possible dementia is to exclude potentially reversible causes. Routine blood tests and possibly also including chest radiography and electrocardiography to rule out cardiorespiratory disease are recommended. A midstream urine sample should also be routinely performed. Metabolic derangements such as hypercalcaemia and hypothyroidism are rarely the causes of dementia in clinical practice, but it is important to identify such causes.

Routine Blood Tests in Primary Care

Routine investigations should include full blood count, erythrocyte sedimentation rate, urea and electrolytes, thyroid function tests, serum B12 and folate. Syphilis serology and HIV testing are not recommended routinely but are justified if an atypical presentation is apparent [22].

19.3.4 Cognitive Assessment in Primary Care

Brief assessment tools are available to objectively assess cognition but they are not diagnostic of dementia. The most commonly used cognitive assessment tool is the

Mini-Mental State Examination (MMSE), with a score of ≤ 24 out of 30 suggestive of dementia [23]. However, adequate performance depends on cultural and educational influences as well as on intact language. In addition, legal copyright issues have limited the use of the MMSE in clinical practice. The test can also be time consuming and therefore less suitable for primary care consultations. Other brief cognitive assessment tools are available. The General Practitioner Assessment of Cognition (GPCOG) test (which is also available electronically) [24], the Mini-Cog Assessment Instrument [25] and the Memory Impairment Screen [26] are clinically robust tools that are more appropriate in primary care [27]. A six-item Cognitive Impairment Test (6-CIT) can also be used and has been found to be more reliable than the Mini-Mental State Examination [28].

19.3.5 Specialist Referral

Memory assessment services, e.g. community mental health teams, memory clinics or geriatric day centres, provide a single access point to multidisciplinary care for individuals suspected of dementia. They will have expertise in diagnosis of dementia subtypes and therefore be able to assess the practicalities and suitability for anti-dementia drugs. These services also have the capacity to assist in early identification and ideally should have a range of assessment, diagnostic, therapeutic and rehabilitation services. Social assessments will also be carried in order to assist families and other carers to help these individuals to live well in the community and support their carers. Multidisciplinary input will also be available for families and carers post-diagnosis and provide monitoring of any intervention started. It is important that memory clinics have the capacity to operate effectively and network with other components of the healthcare system within its locality. Effective communication with the general practitioner is therefore extremely important to assist these individuals post-diagnosis.

19.3.6 Case Study 2: Dementia

A concerned daughter has brought her father in for review in your morning clinic. He had been seen on a number of occasions over the last year for several issues including recurrent falls, low mood and reported fluctuations in cognition. However on each occasion he was able to provide an accurate history of what has been happening, had capacity to consent to investigations and remained very compliant throughout. His daughter however reiterates that he has “bad days” when his memory is poor; he is often drowsy and unable to make decisions about his personal or financial well-being. Given that he was a former head teacher who had always been very disciplined and organised, this was a significant shift in behaviour from his normal self. On further questioning, the patient reports that his sleep has been disturbed by extremely distressing dreams and this was why he was drowsy and lacked

focus. Given this history he is referred to the old age psychiatry team where he is diagnosed as having Lewy body dementia. He is referred for physiotherapy and occupational therapy assessments, joins a local dementia support group to access more information and is referred to the psychology team for further cognitive rehabilitation.

19.4 Long-Term Management in the Community

Following the emergence of symptoms, individuals with dementia live an average of a further 5 years [29]. As no single healthcare team has the expertise to manage the issues associated with dementia care in the community, an integrated multidisciplinary approach needs to be adopted in order to assist these individuals to live well in the community and to ensure their family carers are well supported.

19.5 Information Provision

There are benefits and disadvantages to receiving a diagnosis of dementia; the key issue is for the diagnosis to be timely for the patient and their family. Some will be reassured that the difficulties they have encountered have been given a name. It may encourage them to plan ahead before they lose the capacity to make decisions in the future. Similarly families and carers may find that a diagnosis offers a full and proper explanation for the troubling observations they have witnessed.

For people diagnosed with dementia, accurate information provision to them and their families is key. If required this should be available on local support services and can be obtained from either primary or secondary care services. Unfortunately there is evidence that people with dementia and their families/carers do not receive either sufficient information or receive information in an acceptable format [30]. Voluntary organisations can provide support for patients and their families but their resources are often limited. The Alzheimer's Society (www.alzheimers.org.uk) provides local points of contacts for people with dementia and their carers. They also have a number of publications for patients and clinicians. "The Dementia Guide" is a free, comprehensive publication available to order for anyone who has recently been told they have dementia.

Peer support in dementia has the potential to be of great benefit to people with dementia and their families as they may be able to provide access to information that may not be readily available from their normal points of healthcare access. This could be in relation to, e.g. financial problems where individuals may benefit from signposting to financial or debt service agencies [31].

Providing carer support in the early stages of a patient's cognitive impairment can reduce future problems with depression and enable the carers to better cope with the behavioural problems associated with dementia [32].

19.6 Pharmacological Management

In the UK, following national guidance, pharmacological treatment of dementia is generally started by specialists in the care of people with dementia. Given the potential interactions associated with polypharmacy in a potentially frail older person, these should only be continued when it is considered to have worthwhile cognitive, global, functional or behavioural effect. There are currently two classes of drugs used in symptomatic (Alzheimer's and mixed) dementia. These include acetylcholinesterase inhibitors (AChEI) and N-methyl-D-aspartic acid (NMDA) receptor antagonists. Such medications do not alter the pathogenesis of dementia but do slow the rate of cognitive decline. The emphasis is to improve or maintain function following neuronal damage [33]. Severity of dementia is frequently defined by the Mini-Mental State Examination score (mild 21–26, moderate 10–20, moderately severe 10–14, severe less than 10).

The three AChEI (donepezil, galantamine and rivastigmine) are recommended as options to manage mild-to-moderate AD. If patients are intolerant of AChEI or have moderate or severe dementia, memantine can be started. However only specialists in the care of people with dementia should initiate treatment and only continued when there are perceived benefits to cognitive, global, functional or behavioural symptoms. A shared care protocol is normally locally agreed to ensure patients are reviewed appropriately.

Donepezil is initially given at 5 mg once daily at bedtime. Assessment of treatment should be carried out at 1 month with the dose increased to a maximum of 10 mg once a day if necessary and tolerated. Galantamine is given initially at 8 mg once a day for 4 weeks and then increased to 16 mg once a day for at least 4 weeks. The usual maintenance dose is 16–24 mg once a day depending on clinical benefit and tolerance. Rivastigmine is dosed initially at 1.5 mg twice a day increasing in steps of 1.5 mg twice a day at 2-week intervals. The maximum dose is 6 mg twice a day. Nausea and vomiting tend to be the main side effects of AChEI with donepezil also causing muscle cramps, fatigue and insomnia [34]. The NMDA receptor antagonist memantine is initially given as 5 mg once daily and increased in steps of 5 mg at weekly intervals to a maximum of 20 mg once a day. Common side effects include dizziness, headache and hypertension [34].

The key elements of managing dementia in primary care often lie out with conventional pharmacological treatments.

19.7 Non-pharmacological Interventions

The evidence base for non-pharmacological treatment of dementia is steadily increasing. These include psychosocial therapies, cognitive-based therapies and physical and sensorial therapies, which can be carried out at the patient's home or in their institutional care home [33]. Further advantages of non-pharmacological management include the avoidance of side effects, interaction and limited efficacy

associated with conventional drug therapies [35]. For example, cognitive behavioural therapy can be used in those with mild-to-moderate dementia to overcome “catastrophic thinking” and reduce depressive withdrawal [27].

Cognitive training and rehabilitation are two of the most commonly used non-pharmacological treatments in the earliest stages of dementia. Emphasis is on training specific domains such as memory, attention and executive functions [36]. Cognitive rehabilitation offers a more individualised approach and can enhance functioning in everyday life. Cognitive stimulation therapies (CSTs) offer activities involving cognitive processing often as a group-based activity in a social context [36]. CSTs have been shown to be an effective secondary prevention therapy for older people with mild-to-moderate dementia [35]. CST has also been found to be as cost-effective as dementia drugs. CST comprises cognitive and social skills training, delivered in twice weekly sessions usually over 7 weeks. Information about training including course and information manuals can be found at www.cstdementia.com. Unfortunately due to a shortage of specialist services, psychological therapies may not be as accessible to people with dementia through primary care.

Other non-pharmacological interventions include physical therapies and occupational therapy. Like in other conditions, physical exercise programmes have been shown to be effective particularly as secondary prevention for people with mild-to-moderate dementia [37]. They have the potential to delay onset or slow dementia progression and are currently recommended as part of a care plan to assist people with dementia in maintaining their independence [38]. Occupational therapy (OT) assessment typically involves an evaluation of the severity of the individual’s disability and the effects on daily living. This is usually followed by the modification of the individual’s home and environment and educating the individual on compensatory strategies. A study looking at OT as a potential non-pharmacological therapy in home-based individuals found it to be both cost-effective and cost saving when compared to usual care for people with mild-to-moderate dementia living at home [43].

19.8 Driving and Dementia

A diagnosis of dementia can affect the individual in numerous ways and having a direct impact on their independence, for example, driving. If the patient wishes to continue to drive, they must, by law, inform the Driver and Vehicle Licensing Agency (DVLA). However it must be noted that a diagnosis of dementia does not automatically mean the person with dementia has to stop driving; however they must fulfil certain requirements which may include annual assessments by their GP [39]. It is also important to remember that the stage at which an individual loses the ability to drive safely varies.

Driving is a complex process as the individuals must make sense and then respond to their surroundings appropriately without causing accidents. They must also be able to plan their routes and remember their destination, something that can be difficult for the person with advanced dementia. A driving assessment can be

offered if someone with dementia is unsure of his or her ability to continue to drive. Persons who feel as though they need to stop driving will need understanding and support from their family and carers [39]. Driving may be their only mode of acceptable transportation and the removal of this from their lives could mean a loss of independence.

19.9 Caring for the Carer

Some carers do not formally acknowledge the fact that they are carers as their input is seen as part of their family duties. However carers of people with dementia are more likely to experience depressed mood, to report a higher burden and to have worse physical health, compared with carers of people with other long-term conditions [40]. In dementia, carers may grieve as their relative loses their cognitive abilities and the tangible benefits of companionship, affection and intimacy; this experience has been likened to “coping with a living death”. GPs are often the first point of access and are in prime position to detect those with physical or mental problems because of their caring responsibilities. GPs should therefore endeavour to provide proactive carer support and to monitor their health and well-being, in addition to caring for the person with dementia [41]. If the family carer is a patient on the GP’s list, the GP should record them as a carer and assess their physical, psychological and practical needs.

In England, the 2006 General Practitioner Contract has encouraged such a proactive approach. Practices are rewarded for implementing a management system that includes a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment in accordance with the Carers (Equal Opportunities) Act 2004. Carers expect realistic information about dementia, the implications of diagnosis and its prognosis, and how to make best use of available facilities. Respite care can also be provided regularly or sporadically. This can be in the person’s home, in a centre or in institutional care [41] in response to the needs of the carer. Information about key voluntary organisations such as Dementia UK, with its special Admiral Nursing Services for carers of people with dementia, the Alzheimer’s Society and Carers UK will be helpful. This has been supplemented by the Royal College of General Practitioners (<http://www.rcgp.org.uk/carers>).

The mental and physical health of carers is paramount if community care is to be a realistic, long-term possibility. A meta-analysis of psychosocial interventions for carers of people with dementia revealed that such interventions can reduce psychological morbidity for carers and help their relatives stay at home longer; interventions that were intensive, were individualised and also included people with dementia, as well as their carers, were the most successful [42]; however in terms of actual practice, it is difficult to know what sort of intervention works best for whom and when. Caregiver situations and characteristics need to be considered when individually tailoring flexible interventions in collaboration with the carer. Depression in the carer is one of the factors that influences their ability to keep on caring and should be periodically checked for and appropriately treated.

19.10 Supporting Patients to Live Independently in the Community

In the UK, two-thirds of people with dementia live independently in the community. This can pose significant challenges to primary and social care services. The ability of the individual to continue to live independently in the community may only be achieved through the support offered by neighbours, friends and social support. Medications can be provided through weekly dispensed Dositte boxes through the pharmacist, with any potential interactions and changes to medication readily flagged up as necessary. This can be facilitated through prompts and reminders to help them to remember to take the tablets. Assistive technologies such as tracking devices can be used in coordination with neighbours and friends to assist those who may be found wandering on an infrequent basis. Alarms and pendants can also be used to the same effect particularly if the individual requires prompt assistance. This can help the patient to remain safe at home, reduce the need for hospitalisation and delay institutionalisation which has its own financial implications. Further information on assistive technologies can be found at <http://www.atdementia.org.uk/>.

19.11 Suggested Activities

How do you support the family carers of people with dementia?

Discuss in your team how you raise subjects such as driving, financial planning and care planning with patients with dementia: Could you do it better?

Clinical audit of the physical health care of people with dementia.

Key Points

- Dementia remains a global health concern.
- Governmental strategies are focused on more timely diagnosis and enabling the patients to live in the community for as long as possible.
- Diagnosis can often be difficult; there is still considerable stigma associated with the illness and people may assume their symptoms are due to normal ageing.
- It is important to undertake an examination and investigations to rule out reversible causes of cognitive impairment; prompt referral to specialist services will allow access to earlier treatment and support.
- Pharmacological and non-pharmacological treatments are available but unacceptable variations in service provision exist.
- Factors such as driving and promoting independent living at home through assistive technology, social care packages and carer support need to be maximised.

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