Open Dementia Programme Printable Notes

Module 4: Diagnosis and who can help

Learning aims
On completion of this learning object you will be able to:
• identify reasons why an early diagnosis is important
• describe the emotional impact of receiving a diagnosis of dementia
• describe the process involved in diagnosing a dementia
• list some key dangers of labelling people
• describe the multidisciplinary nature of a robust network of help and support for people with dementia and their families
• describe a range of medical and non-medical treatments in dementia and know how to access more information on them.

Estimated time required: 20 to 30 minutes

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Section 1: Introduction

Hello and welcome to module four, entitled ‘Diagnosis and who can help?’

Frequently on receipt of a diagnosis of dementia, many families are left somewhat confused and unaware of the implications of the diagnosis, what the next steps might be and from where to get help.

This module looks at this process. We will look at the importance of receiving a diagnosis, and follow the experience of some people with dementia who have undergone this process. We will explore how a diagnosis is carried out and look at treatment and both medical and non-medical sources of support.
Section 2: Diagnosis

In this section you will learn about:
• the emotional impact of receiving a diagnosis
• the difficulties experienced in getting a diagnosis
• how diagnosis of dementia is usually a process of elimination
• the pros and cons of revealing a diagnosis.

Personal experiences of diagnosis

It is important to begin this section by learning from the personal experiences of people with dementia.

Read extracts from three interviews below in which people share their experiences of receiving a diagnosis. Once you have read the interviews, reflect on the questions that follow.

Extract 1

John: ‘People I worked with noticed that I was getting worse and worse, so eventually I went to see my doctor. I was sent for a scan and the confirmation was that I did have Alzheimer’s disease.’

Extract 2

Mr Wilson: ‘I was sent for scans and then I got a call to see my consultant and he said, ‘Mr Wilson, you have got Alzheimer’s disease’, and at that moment I broke down and cried. I cried with relief I’d got an answer to what was slowly eating me apart.’

Extract 3

Darrel's husband: ‘You eventually got referred didn’t you to the Neurological and Neurosurgery Hospital in Queens Square in London and they wanted to do all sorts of tests on Darrel, lumber puncture, ECG, genetic tests all that sort of thing.’

Darrel: ‘Mmm.’

Husband: ‘So it took them three years to diagnose Darrel and you know, like other people we weren’t offered…’

Darrel: ‘Mmm.’

Husband: ‘…any care.’

Please note: any word in blue can be found in the accompanying glossary.
Over to you!

1. What differences can you see in each of the three experiences?
2. Why do you think it took three years for one person to receive a diagnosis?
3. What do you think their experience would have been like if diagnosis had been kept from each of them?
4. What might be the benefits or consequences of receiving a diagnosis in each case?
5. How would YOU feel in their shoes?

The process of getting a diagnosis

We’re now going to look at the diagnostic process. To do this, read this extract from a workshop in which Doctor Seb Crutch talks about diagnosing dementia.

As you read think about these two questions:
- How long do you think this process might take?
- How worthwhile is the time spent making a diagnosis?

Extract

Seb: ‘I think mood variation and particularly depression can be very common in people with dementia. I think that’s partly due to the fact that dementia can affect the parts of the brain which help to regulate our mood but also, in part, it might be a reaction to the many ways in which dementia affects people’s lives; the frustrations that those simple everyday tasks which they now can’t perform for themselves and sadness at the way that the condition has caused that their life to have to change.’

Student: ‘So when you are diagnosing dementia, how do you know it is dementia and not something else?’

Seb: ‘Well, there are a variety of different conditions and problems which can cause dementia-like symptoms including things like urinary tract infections, thyroid problems, clinical depression, dehydration and so on… and so it’s very important to make sure that when one’s diagnosing dementia that one’s ruled out all of these sort of treatable conditions which once treated would help the symptoms to resolve. We also do things like giving people brain scans ... not just to identify...’

Please note: any word in blue can be found in the accompanying glossary.
the particular type of dementia that they have but also to rule out causes such as a brain tumour which might be addressed in a different way.

A doctor will generally ask for a detailed history of the problems the person is experiencing, and undertake tests to rule out treatable conditions that could be the cause of the person’s symptoms. These might include depression, an infection, thyroid problems, constipation or vitamin deficiencies.

Additionally, the doctor will usually conduct a psychometric test. The most frequently used psychometric test is known as the Mini Mental State Examination (MMSE).'

Below are some of the questions and activities that the MMSE test incorporates:
- drawing the correct time placement of clock-hands on an image of a clock face
- picking out the correct date from a calendar
- identifying pencils from an image
- spelling the word ‘world’ backwards.

Over to you!

1. When have you ever been put on the spot?
2. How does it feel to have questions fired at you?
3. How do you think a person with dementia might feel being tested like this?
4. What factors other than a dementia do you think might influence the score of an individual?

The MMSE score itself is not a confirmation of diagnosis but forms part of a wider diagnostic process. For a more detailed explanation of the MMSE go to the website for the Alzheimer’s Society at www.alzheimers.org.uk

Many people with dementia have reported how daunting this test is, being asked questions from a total stranger, in a strange environment, when they might have a learning disability or when English may not be their first language. Some people may also receive a brain scan to help clarify the diagnosis, though this can be inconclusive.

It is important to remember that people with dementia do not wish to be reduced to a set of scores or measurements. Being tested can generate feelings of failure and despair.
The poem below asks you to recognise the gifts and strengths of people whose strengths are not always immediately evident.

Cindy

by Nina Herrmann

When you look at me,
You will measure me
... by my awareness
... by my response
... by my age
... by my development.
And you will shake your head
And find me lacking.
But, for me, you are measuring
with the wrong cup.
...
...
So measure me if you must...
But measure me, too, with my cup
And you will find me
full.
Giving labels to people with dementia

Look at the descriptions of the anonymous people below and think about how it might feel to be treated only in terms of the negative label they have been given. An accurate diagnosis would help remove these negative labels. As you have seen from the poem in the previous section, care must be taken not to substitute one label for another and limit a person purely by diagnosis.

The left column shows the labels, while the right one shows the real people behind the labels.

<table>
<thead>
<tr>
<th>Label</th>
<th>Real people</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person 1: ‘Forgetful’</td>
<td>Philip: ‘I was a National Pole Vaulting Champion in my youth.’</td>
</tr>
<tr>
<td>Person 2: ‘Disorientated’</td>
<td>Rose: ‘I am a qualified Tai Chi instructor and can also use martial arts.’</td>
</tr>
<tr>
<td>Person 3: ‘Wanderer’</td>
<td>Anne: ‘I travelled across the whole of Europe on a motor bike and side car.’</td>
</tr>
<tr>
<td>Person 4: ‘Demented’</td>
<td>John: ‘I have travelled and performed all over the world.’</td>
</tr>
<tr>
<td>Person 5: ‘Confused’</td>
<td>David: ‘I won two international awards in military model design.’</td>
</tr>
</tbody>
</table>
The arguments for and against diagnosis

Throughout this section we have looked at the impact and processes involved in obtaining a diagnosis. Do you think there are more arguments in favour of having a diagnosis or against a diagnosis?

Have a look at the table below: it summarises some of the arguments in favour and against.

Arguments for
- Person and carers can be better equipped to deal with the disease.
- A diagnosis is the first step to planning for the future.
- A diagnosis can facilitate access to appropriate help and support.
- An early diagnosis can exclude other treatable conditions or illnesses that cause memory loss.
- A diagnosis can give a greater understanding of the condition and person.
- It can open the gateway to receiving relevant welfare benefits, legal rights.
- A diagnosis can facilitate access to dementia-specific and condition-specific support services.
- It can be a huge relief to finally know what is happening.
- A diagnosis will ensure closer monitoring of medical regime.
- It helps facilitate access to ‘anti-dementia’ drugs as soon as the person becomes eligible for them.

Arguments against
- There is no cure and there’s nothing you can do.
- They’ll only forget they’ve got it.
- What they don’t know can’t hurt them.
- It could cause a catastrophic reaction if they keep getting told.
- Undergoing the process can be harmful to well-being.
- You can only really get 100 per cent accurate diagnosis post mortem.
- Diagnosis may become another label and could distract attention from other conditions that might be causing pain or confusion.

Please note: any word in blue can be found in the accompanying glossary.
Having read the arguments for and against diagnosis, would you change your answer?

A key benefit of an early diagnosis is the resulting access to appropriate help and support.

A detailed history of a person’s condition and symptoms, taken as soon as possible, is a vital component in the diagnostic process. In many cases the condition has been present for months, even years, before people have presented to their GP.

We estimate that there are now 683,597 people with dementia in the UK. This represents one person in every 88 (1.1 per cent) of the entire UK population. Dementia UK (Alzheimer’s Society, 2007).

That brings us to the end of this section. When you are ready, move to the next section where we will look at the help and support available to people with dementia.

‘We estimate that there are now 683,597 people with dementia in the UK. This represents one person in every 88 (11%) of the entire UK population.’

Dementia UK (Alzheimer’s Society, 2007)
Section 3: Help and support

In this section you will learn about:
- the help and support available throughout the journey of living with dementia in a family
- the experience of contact with support services
- the roles and skills of key positions in the dementia care field
- the multidisciplinary nature of support services.

The journey that many families undertake when one member has a dementia can vary widely from case to case.

In this section we will follow the journey of two couples to explore some factors that can have both positive and negative influences on this journey.

We will then look at how a network of support could be built up to enable people to adapt to the changes that dementia brings over time.

The dementia journey: for Lottie and Eric

You are about to meet two couples who will chart their ‘journey’ with dementia. First of all we’re going to meet Lottie and Eric. As you read, think about who might be involved, to help them, at each stage of their journey.

In the beginning

Eric: ‘It sort of crept up on us. We’d never had a cross word in 44 years. First she accused me of taking her housekeeping money – turns out she’d been doing a weekly shop every day. I had to start doing it. When I told her why she had a right go at me. She kept losing things and stopped cleaning like she used to. I don’t mind telling you I had a few good cries. I really thought to myself it was all a sham – had she ever loved me? One morning I caught her sobbing when she woke up, but as soon as I approached her she pushed me away again. It was like treading on egg shells in our house. I had to start doing the cleaning when she wasn’t looking. Of course, she told the doctor she was fine when she saw him.’

Lottie: ‘Oh yes, my memory’s awful! But I am 80, you know. I can still touch my toes and I keep this place spic and span. You can take a look at my kitchen – it’s spotless.’

Please note: any word in blue can be found in the accompanying glossary.
Diagnosis

Eric: ‘My daughter came with us to the GP and told him all the things I couldn’t, and that it had been going on for about two years now. He said he’d refer to a specialist for us. Everyone was really nice but it was all a bit vague. We went to see the consultant who said he’d write to our GP. I didn’t really understand what went on at that consultation. Well, we heard nothing for ages then Lottie got a new prescription for this Aricept sent through, and on the paper it said about Alzheimer’s. Well no one had mentioned that to us or really what it meant. It didn’t stop her driving me mad sometimes, though. Our daughter was a great help and would come and give me a break sometimes. It gave Lottie a break from me too! The community nurse told us we could get benefits but I’ve never been one to scrounge. Looking back I wish I’d taken them up earlier. Still, in sickness and in health, and all that...’

Lottie: ‘I have to take these tablets for my memory. They think I’ve lost me marbles. He won’t let me do anything now.’

Later stages of condition

Eric: ‘Our community nurse is the one I called for advice each time. She persuaded me to get benefits. She got a social worker involved too who said she could arrange someone to come in and get Lottie up and dressed everyday. I said that would not really work as she gets up at all times of the day. Plus, it was too expensive. Lottie had a fall and had to go into hospital. Our community nurse helped have the odd word with the ward. I stayed there every day. The social worker had to persuade me along with everyone else that I couldn’t look after Lottie at home. I knew they were right but I just feel so guilty. Lottie would ask to go home with me when I came. We’d never had a day apart in 44 years and I felt like I was being told my marriage is over. When she went into the home I felt I couldn’t call our community nurse any more and the staff in the home were very nice but didn’t know me or Lottie. It seemed to be ‘case closed’ long before Lottie died a month later.’
Over to you!

Eric and Lottie received a lot of support from the community nurse. 
1. Who could YOU choose to help you build a network of support? 
2. What factors would influence your decision? 
3. Why do you think some people don’t accept some support such as home carers or welfare benefits initially, or at all?

The dementia journey: for Mike and Stella

Now, read about the experience of another couple, Mike and Stella, and watch as an ever wider network of support builds up around them.

You can find out more about each of the items in bold on pages 15 to 17.

Part 1: Early stages

Mike: ‘They sold me down the river at work and pushed me out for incompetence. I was the best teacher they’d ever had at that school. The doctor kept saying it was depression – well I tended to agree. I was getting really down. I first knew it was something more when I went out for a drive and couldn’t find my way home.’

Stella: ‘At 51 Mike started having problems. I thought it was just pressure of work. He’d stay behind at school for hours before coming home to finish off stuff. Then we kept getting red reminders to pay our bills. We tried psychotherapy, all sorts of counselling, convinced it was a breakdown we could work through.

‘Our friends in the neighbourhood were really understanding and supportive. The man in the local papershop wouldn’t make a fuss if Mike went out without paying. I’d always see him straight later.’

Part 2: The time around diagnosis

Stella: ‘It took about four years before anyone thought about Alzheimer’s disease. He was just too young you see so our GP had been ruling everything else out. He immediately referred us to the consultant in old age psychiatry who headed the community
mental health team for older people (CMHT). Then it was a case of trying to find out what help we might get. But that wasn’t easy – everything was geared up for older people. One day I saw a poster from the local Alzheimer’s Society advertising a six-week information programme for carers of people with memory problems. I’d finally found the one-stop-shop I’d needed from the start. The branch advice worker was brilliant. She knew about all the benefits we were entitled to from the Pensions service and the Department for Work and Pensions and helped us complete the applications. She was always our first port of call and if she couldn’t help direct she would signpost us.

‘We were invited to a local monthly support group and the social events they held. It was here I got the idea off another carer to take the car to a disused airfield so Mike could have a go. It was a real highlight!

‘Our branch advice worker did some work with us as a family as Mike had been the patriarch of the family. It helped us look at how things were going to change but also how we could still include Mike in things. It helped us see how to avoid silly arguments and put the blame on the dementia and not on Mike.

‘Mike also instigated the set up of a monthly forum for people with dementia. We built up a good relationship with the branch worker who has been our point of reference all the way through this time. We both learnt about dementia in real layman’s terms – something we can both understand.’

Mike: ‘I was furious Stella was going to this course every week, so I wrote a letter demanding to be included, fully aware as I was of my condition. Well, this got noticed and I became a founding member of the stirrers club. It was such a relief to meet other people who hate being tested and labelled like me!’

Stella: ‘Mike wasn’t too keen on the consultations as he didn’t like the tests. And the nurses from the CMHT (the community psychiatric nurses or CPNs) did much the same when visiting us at home. During the Information programme run by the branch worker we met the occupational therapist (OT) from the community mental health team who did a session on activities. We made sure we would continue our social life as much as possible. Mike carried on in the ramblers club too which was a good break for him. The OT was also keen on reminiscence activities and she was full of useful tips to get Mike on his favourite topics of football and foreign languages.

Please note: any word in blue can be found in the accompanying glossary.
‘The social worker from the council’s older people’s team worked closely with everybody and she was really imaginative in trying to help find a day care place for Mike that was not full of people 25 years older than him. She arranged for him to attend the social services day centre for more physically disabled people. There were many men his own age there and they were all supportive and interested in each other. This worked really well.

‘The local AS branch also had a home respite service which meant Mike had a weekly outing with the respite worker who would generally accompany Mike in the village or out for a walk. They built up a great relationship and it meant weekly contact with someone from the branch which helped me no end.’

**Part 3: Later stages of condition**

Stella: ‘As time went on Mike became much more dependent. Our branch worker advised I contact the social worker again. She was able to set up a programme of home care for us. It was a bit inconsistent at first but with the branch worker’s support we managed to iron out a manageable programme. When Mike had a brief spell in hospital, the branch worker put us in touch with the hospital psychiatric liaison team – part of the community mental health team. They were brilliant and Mike had a pathway laid out for his discharge as soon as he went in, which was just as well because he became terribly confused when he was in there. The transition to a nursing home followed not long after. It was a very worrying time.

‘My own health is not good and Mike deteriorated a lot needing increasing amounts of care. In fact he was assessed for continuing care funding as his needs became more complex but our branch worker was a real advocate with that process and in helping the new home welcome Mike and myself.’

Please note: any word in blue can be found in the accompanying glossary.
Who’s who

Spend some time looking at the table below to find out more about some of the key players in Mike and Stella’s journey.

<table>
<thead>
<tr>
<th>Early stages</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>The doctor (GP)</td>
<td>The general practitioner (GP) is often the first port of call for help. Your GP can carry out some initial diagnostic investigations but it is always important to request a referral to the specialist for further and full investigation into the condition.</td>
</tr>
<tr>
<td>Our friends</td>
<td>It is vitally important not to hide a diagnosis from friends and neighbours. Friends can be so much more understanding and be a greater source of help throughout the course of an illness.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The time around diagnosis</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultant in old age psychiatry</td>
<td>The GP should always refer to these specialists for full investigation and treatment of any possible dementia. They are the clinical heads of the community mental health teams.</td>
</tr>
<tr>
<td>Community mental health team for older people (CMHT)</td>
<td>A specialist National Health Service team headed by the consultant providing clinical support for people with dementia and their carers in the community. Works very closely with social services.</td>
</tr>
<tr>
<td>Local Alzheimer’s Society (AS)</td>
<td>There are nearly 300 branches nationwide, providing a wide range of support services for people with dementia and their carers. To contact your nearest look up <a href="http://www.alzheimers.org.uk">www.alzheimers.org.uk</a></td>
</tr>
<tr>
<td>Information programme</td>
<td>Many AS branches provide regular programmes that provide an introduction to dementia with information on accessing and navigating services.</td>
</tr>
<tr>
<td>Home respite service</td>
<td>The service that provides the home respite workers – often run by social services or a local AS branch.</td>
</tr>
<tr>
<td>The Pensions Service</td>
<td>Part of the Department for Work and Pensions, the local pensions service can be very helpful with more complicated entitlement. To find out more look up <a href="http://www.thepensionservice.gov.uk">www.thepensionservice.gov.uk</a>.</td>
</tr>
<tr>
<td><strong>Department for Work and Pensions</strong></td>
<td>This is the government agency that awards non-means-tested benefits to people with dementia. Contact 08457 123 456 or go to <a href="http://www.dwp.gov.uk">www.dwp.gov.uk</a>.</td>
</tr>
<tr>
<td><strong>Monthly support group</strong></td>
<td>This is a regular chance for carers to meet up and share experiences with others. Contact your local AS branch for details of regular groups.</td>
</tr>
<tr>
<td><strong>Occupational therapist</strong></td>
<td>A qualified health service professional, part of the CMHT, who specialises in helping adapt the physical environment to help maintain independence (ramps, grab rails, bath chairs). Expert in provision of activity.</td>
</tr>
<tr>
<td><strong>Branch advice worker</strong></td>
<td>A valuable resource in all Alzheimer’s Society (AS) branches who can provide help, advice, information and access to support services throughout the course of an illness.</td>
</tr>
<tr>
<td><strong>Respite worker</strong></td>
<td>These workers regularly visit people with dementia in their own homes to provide a break for both the carer and the person. These can be accessed through your local AS branch or social services.</td>
</tr>
<tr>
<td><strong>Forum for people with dementia</strong></td>
<td>An opportunity for people with dementia to share and provide mutual support, social stimulation in a non-threatening environment. Provided by many health services and AS branches.</td>
</tr>
<tr>
<td><strong>Community psychiatric nurses</strong></td>
<td>Qualified mental health nurses, part of the community mental health team reporting to the consultant and providing clinical support to people with dementia and carers.</td>
</tr>
<tr>
<td><strong>Social worker</strong></td>
<td>Part of your local council’s adult social care older person’s team. The social worker helps create and coordinate a tailored package of care for families. Works very closely with the CMHT and organisations such as the AS.</td>
</tr>
<tr>
<td><strong>Social services day centre</strong></td>
<td>A good day centre can welcome people for a full day, with structured activities and social engagement for its members. Places available through your social worker.</td>
</tr>
</tbody>
</table>

**Later stages of condition**

| **Home care** | A service delivered to people with dementia in their own homes to assist with personal care, washing, dressing, meals and medication. |
**Hospital psychiatric liaison team**
A mental health nursing service providing specialist support to acute hospital wards with patients with dementia.

**Nursing home**
Usually large houses providing round the clock long-term care for those people unable to be maintained in their own homes.

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**Over to you!**

1. What differences and similarities are there between Stella and Mike’s journey and that of Eric and Lottie?

Please note: any word in blue can be found in the accompanying glossary.
More support options

In Mike and Stella’s case study we have shown how a large network of support can be built up. This is by no means exhaustive and people in different situations may require different resources at different times. For example, for people living alone with dementia a support network could, and often does, include the people and services in the list below.

<table>
<thead>
<tr>
<th><strong>Admiral Nurses</strong></th>
<th>Specialist dementia nurses, available in some areas, working in the community with families, carers and supporters of people with dementia. ‘Admiral Nursing Direct’ provides telephone information and support. For more information, go to <a href="http://www.dementiauk.org">www.dementiauk.org</a></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sheltered or extracare housing</strong></td>
<td>These are often groupings of self-contained flats, which may also include the provision of an in-house home care service (in ‘extracare’ housing) to assist people to maintain their independence for as long as possible. Couples can also live in extracare housing.</td>
</tr>
<tr>
<td><strong>Assistive technology</strong></td>
<td>The term ‘assistive technology’ refers to ‘any device or system that allows an individual to perform a task that they would otherwise be unable to do’. Assistive technology ranges from very simple tools, such as calendar clocks and touch lamps, to high-tech solutions such as satellite navigation systems to help find someone who has got lost.</td>
</tr>
<tr>
<td><strong>Telecare</strong></td>
<td>Telecare is the remote and automatic support system for independent living. Devices range from those where the user presses a button that raises an alert at a control centre, to systems that monitor the person’s well-being and/or environment and which trigger a warning that the person’s well-being has deteriorated, or that an untoward event has occurred.</td>
</tr>
<tr>
<td><strong>Advocacy services</strong></td>
<td>Independent services that aim to give voice to those people with dementia, or carers in the face of often complicated health, financial and social service systems.</td>
</tr>
</tbody>
</table>
Improving support networks: national policy

The National Dementia Strategy for England (produced in February 2009) has the potential to ensure that every person with a dementia and their carers can access such a wide network of support services and care. It calls for improvements across three areas:

• improved awareness
• earlier diagnosis
• higher quality of care.

It is important to remember that people can fare very well with dementia, given the right support at the right time. The network of resources discussed in this section was by no means exhaustive and depending on the particular needs of individuals and their families, many more different resources may be accessed, such as palliative care services, counselling support or specialist nutritional advice.

‘Knowing what I know now about the support available, I would not have been so terrified about the future as I was four years ago.’
Words of an anonymous carer spoken to the author, 2007

That brings us to the end of this section. In the next section we will explore current medical and other non-medical treatments for dementia.
Section 4: Treatments

In this section you will learn about:

- medications and their purpose and use in dementia care
- non-medical interventions in dementia care
- how to access information on a wide range of topics in dementia care.

Question time

In this section, a range of people involved in dementia care put dilemmas about responding to dementia or treatment to our co-authors. For each question, they also suggest helpful reading tips.

Question

‘My dad just wants to go on about his old job. He retired 30 years ago. What’s the point of that?’

Answer

As the ability to form new memories is diminished in a person with dementia, they may have difficulty holding a conversation about present-day events and may feel daunted if pressed. They could, however, talk in much more detail when prompted to talk about childhood, early adulthood, achievements and events from the past that have strong emotional ties. For many people emotional memory lasts longer than practical memory.

Memory prompts can take many forms:

- old objects, for example from the 40s or 50s
- the use of music relevant to a person’s generation
- photographs, old magazines, newspapers and films
- the use of smells (old soaps, herbs, polish)
- poetry – many people remember large extracts of poems learned when at school.

For more detail on reminiscence activities, how to access reminiscence materials, building up life history and memory boxes and group activities read Memories are made of this: Reminiscence activities for person-centred care (Heathcote, 2007).

Please note: any word in blue can be found in the accompanying glossary.
Question

‘I’m told most of the residents in the home where I work have to be on sedatives because they’d be unmanageable.’

Answer

Drugs used for depression and behavioural symptoms include:

- neuroleptics/antipsychotics (major tranquillisers): associated with numerous and serious side effects and can cause rapid decline in cognitive function
- antidepressants: there is very little evidence as to their value
- benzodiazepines (sedatives): some effectiveness seen over a very short period only. Five-fold increase in risk of serious falls
- antiepileptics (mood stabilisers): these may reduce agitation but cause marked sedation and increase risk of falls (Fossey and James, 2008).

These drugs should be avoided unless absolutely necessary. When the perspective of the person with dementia is taken into account, and the person has frequent opportunities to engage in interesting and stimulating activities, drug treatment is rarely necessary. To read more go to: www.alzheimers.org.uk/factsheet

Question

‘I want to know what sort of activities you can do with people with dementia.’

Answer

Some activities for people with dementia may be structured and planned, but activities also need to be an ongoing part of each day to bring meaning, structure and a sense of purpose to individuals.

Suitable activities promote the use of an individual’s strengths and engage their interests. Work-related activities and chores can help people to feel useful. There are a wide variety of different activities including music, arts, food, massage, things to do at home, community outings and gardening.

Engaging in activity helps people to maintain a normal existence. A comprehensive resource on activities is The Alzheimer’s Society book of activities (Knocker, 2007).

Go to www.alzheimers.org.uk/dementiacatalogue for more information on doll therapy, pet therapy and dance.

Please note: any word in blue can be found in the accompanying glossary.
Question

‘I’m worried about my wife. She’s not been eating even when I make her favourite. Have you got anything?’

Answer

Common problems with eating in dementia, such as refusal, are more likely due to oral discomfort, swallowing difficulties or incorrect signals in the brain, than any deliberate attempt to be awkward.

Calm, flexible and inclusive mealtimes are a key way to promote a healthy balanced diet. It is often overlooked as a treatment, but the consequences of a poor diet can be serious – for example, malnutrition, constipation, dehydration and increased confusion.

Foods with strong flavours are surprisingly popular during later stages. For people who are restless, regular snacks or finger foods could be much better than an elaborate sit-down meal.

For more information go to www.alzheimers.org.uk/factsheet/511

Question

‘My uncle has Alzheimer’s disease. I want to find out if these anti-dementia drugs can reverse the deterioration.’

Answer

No drug treatments can provide a cure for Alzheimer’s disease. However, drug treatments have been developed that can improve symptoms, or temporarily slow down their progression in some people.

They are Aricept (donepezil hydrochloride), Exelon (rivastigmine), Reminyl (galantamine) and Ebixa (memantine).

The most recent guidance from the National Institute for Health and Clinical Excellence (NICE) on anti-Alzheimer’s drugs recommends that people in the moderate stages of Alzheimer’s disease should be given treatment with Aricept, Exelon or Reminyl but they recommend that Ebixa should only be used in clinical trials.

For more information see www.alzheimers.org.uk/factsheet/407

Please note: any word in blue can be found in the accompanying glossary.
**Question**

‘I’m trying to find out if a hand massage or pampering with scented oils will have any effect on my gran.’

**Answer**

There is evidence that some complementary therapies might be beneficial for people with dementia. Some of the most commonly used are massage, aromatherapy, which has been effective in reducing agitation, and bright light therapy. It has been suggested that the benefits of aromatherapy do not come through its smell, rather it is thought that chemicals in the oils are absorbed into the lung and pass quickly to the brain (Bradley, 2008).

To access many and more detailed articles on a whole range of complementary therapies go to www.alzheimers.org.uk/dementiacatalogue where you can search topics such as herbal medicines, acupuncture, reflexology and reiki.

**Question**

‘I visit this couple and they’re always at each other’s throats. I know they love each other but they seem to be struggling.’

**Answer**

Living with dementia can raise many difficult feelings. People find it hard to make sense of what is happening to them and how their life is changing. Counselling may offer someone with dementia the opportunity to share their feelings and work out ways to live with their condition.

Traditional counselling expects clients to have full use of their cognitive abilities. However, people with significant changes in their cognition can still respond well to the emotional content of the counselling sessions. Counselling can also help carers to explore their feelings in confidence, outside their network of friends and family.

For more information on this, go to www.alzheimers.org.uk/factsheet/445

Historically, people with dementia and their carers have been treated in isolation of each other and services have tended to separate partners (respite, day care, hospital-based assessment).

Please note: any word in blue can be found in the accompanying glossary.
Approaches that address the effects of dementia on a family dynamic or upon the quality of a relationship between a couple have become known as ‘relationship-centred care’. Without such an approach many antagonisms within a relationship remain unattended, leaving families in a draining cycle of conflict, with some even questioning the validity of decades of marriage. Work on a relationship-centred approach has begun to appear more frequently with the recognition that whole families need to sit down together to express their needs (Marriot, 2000; Sheard, 2004; Murphy, 2005).

Updating knowledge

To round off this section and this module, review the quote below. As you do so, note what is said about the need for care providers to be constantly updating their knowledge.

‘I think it’s important for people who work with people with dementia to keep up-to-date with ideas and knowledge in the field of dementia, both to improve their own clinical practise, but also because information provision is a really important part of looking after both people with dementia and their partners and family.’

Numerous resources have been identified in this chapter, which we hope will not only to help you to update your knowledge but also to share it with others.

We have now reached the end of the fourth module. We have covered the process of diagnosis, and looked at what help is available for people with dementia and their carers. Finally we have highlighted the availability of extensive resources where you can find the most up-to-date knowledge on dementia related topics.

Below is a summary of the main points from this module:

- Diagnosis can help many people prepare better for the journey ahead.
- Diagnosis is important to promote a greater understanding of the condition.
- Undergoing a diagnosis can itself be harmful to well-being and self-esteem.
- People with dementia should not be reduced to a label.
- A large and flexible multidisciplinary network of help and support can be built up.
- Every family’s journey through dementia is unique.
- There is a wide variety of treatments and approaches that can be used to cater for individual needs.

Before you move on to the fifth module of the programme, where we will address common difficulties and how to help, why don’t you do our self-assessment quiz, which will allow you to test your understanding of some of the key points?

Please note: any word in blue can be found in the accompanying glossary.
Section 5: Self-assessment

This self-assessment will allow you to test your understanding of some key messages and facts covered in this module. Choose between true and false for each question. You will then see the right and some feedback on page 27, and where to look in this module to review.

<table>
<thead>
<tr>
<th>Question 1</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Giving a diagnosis is not important.</td>
<td></td>
</tr>
<tr>
<td>True</td>
<td></td>
</tr>
<tr>
<td>False</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Question 2</th>
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</tr>
</thead>
<tbody>
<tr>
<td>A memory test alone can confirm a diagnosis of dementia.</td>
<td></td>
</tr>
<tr>
<td>True</td>
<td></td>
</tr>
<tr>
<td>False</td>
<td></td>
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</tbody>
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<table>
<thead>
<tr>
<th>Question 3</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Once someone is diagnosed it is important not to label them as a person with dementia and nothing else.</td>
<td></td>
</tr>
<tr>
<td>True</td>
<td></td>
</tr>
<tr>
<td>False</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Question 4</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>It is generally better to hide a diagnosis from friends and neighbours.</td>
<td></td>
</tr>
<tr>
<td>True</td>
<td></td>
</tr>
<tr>
<td>False</td>
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</table>

<table>
<thead>
<tr>
<th>Question 5</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>People can fare very well with dementia.</td>
<td></td>
</tr>
<tr>
<td>True</td>
<td></td>
</tr>
<tr>
<td>False</td>
<td></td>
</tr>
</tbody>
</table>

Please note: any word in blue can be found in the accompanying glossary.
| Question 6 | No drug treatment can provide a cure for Alzheimer’s disease. |
| True | False |

| Question 7 | Sedatives should be used to make people manageable. |
| True | False |

| Question 8 | Complementary therapies are of no benefit whatsoever. |
| True | False |

| Question 9 | Eating problems are normally a deliberate attempt to be awkward. |
| True | False |

| Question 10 | Work-related activities and chores can help a person with dementia feel useful. |
| True | False |

Please note: any word in blue can be found in the accompanying glossary.
Answers

1. The answer is ‘false’. Diagnosis is extremely important in promoting understanding, allowing people to prepare for the future and access services. You can re-visit Section 2 ‘Diagnosis’ where we address this subject.

2. The answer is ‘false’. A memory test is only a small part of a much larger diagnostic process. You can re-visit Section 2 ‘Diagnosis’ where we address this subject.

3. The answer is ‘true’. A person with a varied life history and a whole range of strengths and gifts should not be limited by a diagnostic label. You can re-visit Section 2 ‘Diagnosis’ where we address this subject.

4. The answer is ‘false’. Friends and neighbours can be so understanding and a valuable support. You can re-visit Section 3 ‘Help and Support’ where we cover this point.

5. The answer is ‘true’. With the right support at the right time a broad network of support can be built up. You can re-visit Section 3 ‘Help and Support’ where we cover this point.

6. The answer is ‘true’. There are treatments that can slow down the process and temporarily improve the condition for some people. You can re-visit Section 4 ‘Treatments’ where we cover this point.

7. The answer is ‘false’. Sedatives and tranquillisers should be avoided unless absolutely necessary. You can re-visit Section 4 ‘Treatments’ where we cover this point.

8. The answer is ‘false’. Complementary therapies such as aromatherapy, for example, have been effective in reducing agitation in some cases. You can re-visit Section 4 ‘Treatments’ where we cover this point.

9. The answer is ‘false’. Problems such as refusal are more likely to be due to oral discomfort, swallowing difficulties or faulty signals in the brain than any deliberate attempt to be awkward. You can re-visit Section 4 ‘Treatments’ where we cover this point.

10. The answer is ‘true’. Such activities as an ongoing part of a day can bring meaning, structure and a sense of purpose to individuals. You can re-visit Section 4 ‘Treatments’ where we cover this point.

Please note: any word in blue can be found in the accompanying glossary.
Section 6: References


In Their Own Words. The real life experiences of those affected by dementia’. 2008 [DVD] London: Alzheimer’s Society.


Please note: any word in blue can be found in the accompanying glossary.