

Chapter 1

Checking Out the Facts on Dementia

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If you're reading a book about dementia, you first need to understand what the term means. In my work as a family doctor I meet people with a whole heap of different ideas about what sort of condition the word 'dementia' suggests. For some, it's the diagnostic label you give to people who keep having 'senior moments' and regularly forget what they've been up to, where they put their spectacles and the names of their grandchildren. To others, it refers to people who are old and confused, have urine-drenched armchairs, and spend all day shouting at the telly and letting their friends and neighbours know exactly what they think of them.

While some of the above symptoms clearly can be part of the picture, neither of the people described fits the diagnosis. The first is probably just forgetful but otherwise well, and the second may simply be leaky and bad-tempered, with a poor sense of smell. Dementia has a very clear definition, because the diagnosis is never made lightly.

This chapter looks in detail at what dementia is and what it certainly is not.

Understanding What Dementia Is

Dementia isn't a single entity, but the result of a number of different medical conditions that affect normal brain functioning.



The World Health Organization (WHO) defines dementia thus:

[A] syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.

This definition, however, still contains a fair amount of medical jargon. So I'll try to come up with a simpler, but still accurate, version by considering each of the key terms used by the WHO:

- ✔ **Syndrome:** This word describes the symptoms that are characteristic of a particular medical condition. People with the condition have most of these features but don't have to show all of them to receive the diagnosis. Thus in dementia, one person may have poor memory for shopping lists but still be able to add up the prices on the bill, while another may have problems with both memory and calculations.
- ✔ **Chronic and progressive:** These terms mean that the condition is long term and gets steadily worse with time. Many people think that the word 'chronic' means that something is severe. But while dementia may be severe for some people, it's mild in others; chronic here means long-lasting.
- ✔ **Consciousness:** Used in relation to dementia, this word takes on both of its meanings. People with dementia are both awake (as opposed to unconscious) and mentally aware of their surroundings, although what's going on around them may not always make sense and may be confusing.



So dementia can be caused by a number of diseases of the brain that lead to a collection of progressively worsening symptoms affecting a person's thought processes, mood and behaviour; eventually, the person may lose the ability to carry out the basic tasks of daily living.

Grasping What Dementia Is Not

Many myths and misunderstandings circulate about dementia. And to get a grasp of what dementia actually is, it's important to have a clear idea about what it certainly isn't. So here's a selection of some of the most common misconceptions, to help sort fact from fiction.

- ✔ **All old people get dementia.** Although the chances of developing dementia do increase as we get older, it's not a normal part of the ageing process. In fact only 1 in 14 people over the age of 65 and 1 in 6 over 80 suffer from it.

- ✔ **Dementia is the same as Alzheimer's disease.** Alzheimer's disease is just one of a number of brain diseases that lead to dementia.
- ✔ **Memory loss equals dementia.** Dementia does affect memory, but for someone to be diagnosed with the condition he needs to show many other more complex symptoms rather than simply poor memory alone.
- ✔ **Everyone with dementia becomes aggressive.** While some people with dementia can become agitated, aggression isn't a universal feature of dementia and is usually triggered by the way someone is treated or communicated with rather than being a symptom of the dementia alone.
- ✔ **A diagnosis of dementia means a person's life is over.** Despite the fact that the condition is chronic and progressive, many medical, social and psychological treatments and strategies are available to help make life as fulfilling as possible for someone with dementia, for many years.
- ✔ **Everyone with dementia ends up in a nursing home.** While one third of people with dementia do eventually need this level of intense care in the latter stages of their condition, many people are able to access enough help and support to spend the rest of their lives in their own homes.
- ✔ **My nan has dementia, so I'm going to get it too.** Some forms of dementia do have a genetic component and so may run in families, but these are in the minority. For most people, it doesn't follow that because a relative has dementia, they'll get it too. And contrary to what one patient of mine thought, you can't catch it off your nan either!

Looking at the Statistics

Now that I've excluded all the people who don't really have dementia from the discussion, I can look more accurately at what the statistics reveal about who actually has the diagnosis. And, unfortunately, the results still make rather sobering reading.

The statistics tell us that every four seconds, someone in the world is diagnosed with dementia. That's 15 people per minute, 900 per hour and 1,350 during a 90-minute game of football or an average-length Hollywood blockbuster. In fact, by the time you go to bed tonight, around another 21,600 people will have been told they have dementia in the previous 24 hours. Over the course of 12 months, that's a whopping 7.7 million new cases.

And, worse still, those people are just the tip of the diagnostic iceberg, because it's reckoned that up to six out of ten people with dementia may still be undiagnosed in the UK alone. Start adding those figures into the calculations, and the statistics start to look even more frightening.

Without being sensationalist, knowing what we're all up against is important, not only so that governments and health professionals can plan for the types of care that may be needed as the disease becomes more common, but also to enable individuals and their families to be reassured that they're by no means alone in their struggles.

According to statistics from the organisation Alzheimer's Disease International:

- ✔ Currently, 44.4 million people around the world are living with dementia.
- ✔ The number of people living with dementia is expected to double by 2030 and treble by 2050.
- ✔ Sixty-two per cent of people with dementia live in developing countries, a proportion that's expected to rise to 71 per cent by 2050.
- ✔ In economic terms, the cost of dementia care is \$600 billion worldwide, which means that
 - If dementia was a country, it would be the world's 18th-largest economy, sandwiched between Turkey and Indonesia.
 - If dementia was a multinational company, it would be the biggest in the world, out-grossing both Walmart and Exxon Mobile.
- ✔ The increase in diagnoses will hit different parts of the world more significantly than others; thus an estimated 90 per cent increase will occur in Europe, 226 per cent in Asia, 345 per cent in Africa and 248 per cent across North and South America.
- ✔ More worrying still, out of the 193 member countries of the World Health Organization, only 13 have a national dementia plan – and none of these are in Africa.

The statistics for the UK, provided by Alzheimer's Research UK and the Alzheimer's Society, show the extent to which people in this country contribute to the worldwide dementia figures:

- ✔ Currently, 820,000 people in the UK have dementia, meaning that 25 million people know a friend or relative with the condition.
- ✔ The number of people in the UK with dementia will at least double by 2050.
- ✔ Two-thirds of the people with dementia in the UK are women.
- ✔ Dementia costs the economy £23 billion per year, which is more than cancer and heart disease combined; this funding equates to an average of more than £27,000 per person with dementia each year.
- ✔ Despite the increased cost of treating dementia, investment in dementia research is almost 12 times lower than for cancer (£50 million versus £590 million per year).

Looking at the Link between Age and Dementia

A clear correlation exists between increasing age and the chances of developing dementia. In fact, fewer than 2 per cent of people are diagnosed under the age of 65. The Alzheimer's Society suggests that the figures can be broken down as follows:

40–64	1 in 1,400
65–69	1 in 100
70–79	1 in 25
80+	1 in 6

The obvious question is whether dementia will become more common as we live longer. Thanks to advances in science, medicine and technology, as a species we're living increasingly longer. Life expectancy until 30,000 years ago is believed to have been less than 30 years, and right up until the 1800s it was common for adults to die by the age of 40. Now the average man in the UK can expect to live for 78.9 years, while a woman can make it to the ripe old age of 82.7.



These figures represent an average, and life expectancy across the UK varies depending on levels of poverty and deprivation. To the same extent, life expectancy in some countries is much lower than in the UK; in Chad, for example, it is, unbelievably, still only 49.5.

Over the next few decades these figures are expected to rise along with the proportion of older people in the population as a whole. According to government figures, currently 10 million people in the UK are over 65 years of age. By 2035, it's estimated that another 5.5 million more elderly people will be resident in the UK, rising to around 19 million by 2050.

A boy born in the UK in 2030 will have a good chance of living until he's 91, and a girl to 95. Given the rising chance of developing dementia with age, it's feared that cases will become far more common as a result of this boom in life expectancy.

Realising that Dementia Doesn't Just Mean Alzheimer's

One of the commonest misconceptions about dementia is that it equals Alzheimer's disease. Alzheimer's disease certainly does equal dementia, but numerous other causes of dementia also exist.

Also consider mild cognitive impairment, which is not yet dementia but not part of the normal ageing process either. For 40 per cent of those who show signs of cognitive impairment, dementia is unfortunately their next step, but for the remainder, their symptoms will either not develop further, or may even be reversible if they are due to depression or the effects of an acute infection.

Considering the 'big four' types of dementia

On safari in Africa, the guides bust a gut to make sure that you get the best chance of glimpsing the so-called 'big five': lions, African elephants, Cape buffalo, leopards and rhinoceros. Dementia can be broken down into the 'big four': Alzheimer's disease, vascular dementia, Lewy body disease and frontotemporal dementia. Below is a quick field guide to each. (Chapter 3 describes each type of dementia in detail.)

Alzheimer's disease

Alzheimer's disease is the really big one and the most common cause of dementia worldwide. In the UK it's the cause of dementia in 62 per cent of cases, accounting for the symptoms of around 420,000 people.

Alzheimer's is a physical disease that leads to the production of abnormal protein deposits in brain cells, called plaques and tangles. These deposits stop the cells working effectively and eventually kill them off. As the disease progresses, this damage spreads to different parts of the brain, adding to the severity of the symptoms. Symptoms involve changes in memory and other thought processes, alteration of mood and loss of ability to carry out tasks needed for day-to-day living.

Vascular dementia

After Alzheimer's disease, *vascular dementia* is the next most common cause of dementia, affecting about 112,000 people – roughly 17 per cent of the total cases of dementia in the UK. It occurs because of damage to blood vessels around the brain, which in turn limits blood flow and thus oxygen supply to brain cells.

Symptoms are similar to those seen in Alzheimer's disease, but depend on which parts of the brain the reduced blood flow affects. A person who has experienced strokes may also suffer with additional weakness or even paralysis of limbs and speech difficulties.

Because circulation problems become more common as we get older, 10 per cent of people have what's described as *mixed dementia*, where they have Alzheimer's disease alongside vascular dementia, and a mix of symptoms of both.

Lewy body disease

A much rarer sighting, people with *Lewy body disease* make up only 4 per cent of the number of dementia cases – an estimated 25,000 people. Lewy bodies are protein deposits that damage brain cells. They're also found in the brains of people with Parkinson's disease, and as a result an overlap exists in the symptoms of people with these two conditions.

The symptoms of Lewy body dementia are similar to those of Alzheimer's, but sufferers also develop muscle stiffness, tremors and shakiness in their limbs, and slower movement. They can also experience visual hallucinations, commonly seeing animals or people around them that aren't really there.

Fronto-temporal dementia

Fronto-temporal dementia is the smallest of the 'big four', affecting 11,000 people in the UK and representing around 2 per cent of total dementia cases. It's also the most likely of the four types of dementia to be diagnosed in people under the age of 65.

This type of dementia is named because of the areas of the brain that it affects most: the frontal and temporal lobes. These areas of the brain are involved in memory and personality. Thus fronto-temporal dementia shares many of the features of Alzheimer's disease, but has other symptoms, including strange or sexually disinhibited behaviour, lack of empathy, poor personal hygiene, apathy and loss of motivation, increased appetite for sweet or fatty foods, and repetitive and compulsive speech and actions.

Mild cognitive impairment: Dementia lite?

Dementia clearly isn't simply a memory problem, because it affects other thought processes along with mood and the ability to carry out all sorts of everyday tasks. Mild cognitive impairment is often seen as a diagnosis that lies somewhere between full-on dementia and the limitations that occur as a result of a normally ageing brain.

Like dementia, mild cognitive impairment can affect a variety of normal thought processes, but it doesn't impact mood or a person's ability to perform day-to-day functions. And, while it can be a sign of impending dementia for many, especially those with Alzheimer's disease, around 60 per cent of people who develop mild cognitive impairment don't get any worse.

The normally ageing brain

It's no secret that as we get older bits of us start to wear out and don't work quite as well as they once did. Joints become creakier, backs ache, eyesight isn't quite as clear, hair falls out or goes grey, once excitable parts of the body barely raise a smile and memory isn't as sharp as it used to be.



Failing memory was once thought to result simply from a progressive loss of brain cells as we get older, but that's no longer believed to be the case. Research now suggests that unless people have a disease that wipes out their brain cells, they die with the same number that they started life with. And while human brains do shrink in overall size – by about 10 per cent during adulthood – that loss of volume isn't the only culprit behind memory problems.

A combination of factors actually conspire to create the infamous 'senior moments'. These include a reduction in the effectiveness of the communication between nerve cells that whizz information around the brain, an increase of inflammation in brain tissue in response to infection and disease, a reduction in blood supply, and the damage caused by a lifetime's contact with free radical molecules such as oxygen and nitrogen in the atmosphere.

Add these factors to the shrinkage, and you have the recipe for the wear-and-tear type changes we see in the ageing brain as reflexes become slower and people take much longer to finish a crossword than they used to. It's normal, although by no means universal, for people to notice these changes. Some people don't experience even this level of deterioration and are as sharp as tacks well into their 90s (and even beyond).

The abnormally ageing brain

In a person with *mild cognitive impairment*, the symptoms are more significant than those just described for normal ageing. It's not uncommon for people to notice the following:

- ✓ Forgetfulness
- ✓ Difficulty following conversations
- ✓ Declining ability to make sensible decisions
- ✓ Getting lost easily
- ✓ Poor concentration and attention span

The severity of mild cognitive impairment and its progression towards full-on dementia can be charted using the Global Deterioration Scale (GDS) developed by Dr Barry Reisberg in 1982. This score has seven stages:

- ✓ **Stage 1:** No problems identified by doctors or the patient.
- ✓ **Stage 2:** The patient recognises that he has a problem, perhaps with remembering names, but he scores normally on diagnostic tests.
- ✓ **Stage 3:** Subtle problems carrying out thought processes start to affect work and social activities. Tests may well begin to pick up problems (this is mild cognitive impairment).

- ✔ **Stage 4:** Clear-cut difficulties develop in terms of memory and carrying out tasks such as dealing with finances or travelling. Denial is common. Early dementia has set in.
- ✔ **Stage 5:** The person needs some assistance but is still quite capable of washing, dressing, eating, going to the toilet and choosing appropriate clothes. Forgetfulness in relation to names and places is becoming more severe.
- ✔ **Stage 6:** The person is largely unaware of anything that's happened to him in the recent past. He needs help with most of the basic activities of daily living and may need to be looked after in a care home. Incontinence is common.
- ✔ **Stage 7:** By this stage the person is experiencing severe dementia. He's completely dependent on others for everything, often including mobility. Verbal communication skills are extremely restricted.

Recognising the causes of mild cognitive impairment and taking steps to avoid it

Some cases of mild cognitive impairment are caused by the development of similar protein deposits to those found in Alzheimer's disease. This finding is perhaps not surprising, considering that those people who go on to develop dementia mostly have Alzheimer's disease. Other brain changes noted include worsening blood supply and shrinkage of the part of the brain called the hippocampus, which is involved with memory.

Brain training

A multi-million-pound industry has developed producing specially designed 'brain-training' games and puzzles in response to people's increasing fear of developing dementia.

In 2009, the Alzheimer's Society in the UK teamed up with the BBC science programme *Bang Goes the Theory* to carry out a large-scale experiment looking at the effect of brain training on planning, problem solving and memory. The experiment, 'Brain Test Britain', gathered results from 13,000 people, which were then published in *Nature*, the eminent science journal.

The results clearly showed that while the brain-training exercises made people better at the particularly tasks they were performing, these skills weren't transferred to other brain skills such as memory and planning. And while the research is continuing for the over 60s, the advice for those worried about cognitive impairment is to save money on these specialised products, because they offer no more benefit than do simple crosswords and puzzles.

No specific treatment for mild cognitive impairment exists and, in particular, no evidence suggests that the drugs used to treat Alzheimer's disease are any use. You can gain some mileage, however, by addressing risk factors for poor circulation, by controlling your blood pressure, eating a low-fat and high-fibre diet, quitting smoking, drinking alcohol within the limits of recommended guidelines and taking regular physical exercise.



Some evidence suggests that keeping the brain mentally active by doing word and number puzzles, reading and maintaining stimulating hobbies and social activities can help too.

Considering Copycat Conditions

A whole host of medical conditions can trigger symptoms in people that are very similar to dementia but don't fit the full diagnostic criteria for it. These conditions often cause confusion and can stop people functioning normally in daily life, but they're largely reversible with correct treatment and thus, thankfully, aren't progressive in the same way as dementia is.

When people visit their doctor with symptoms that could mean dementia is setting in, they undergo a number of initial investigations involving blood and urine tests. Such tests are performed to rule out any reversible causes – most frequently, conditions that either affect the brain and nervous system or result from derangements of various bodily hormones. Acute infections can also trigger confusional states, and long-term alcohol abuse can lead to problems with memory (alongside its more commonly seen propensity to render people confused and disorientated).

Neurological causes

Some of the most well-known medical conditions affecting the brain and nerves have symptoms that can mimic some of the features of dementia alongside their own, more specific features. So doctors may want to rule some of these diseases out of their enquiries before coming to a final diagnosis:

- ✓ **Parkinson's disease:** This condition does have a genuine overlap with dementia, because people with Parkinson's disease have a higher-than-average risk of also developing dementia. In fact, Parkinson's disease-related dementia accounts for 2 per cent of all cases.

The symptoms of Parkinson's disease-related dementia are very similar to those of Lewy body disease, and researchers think that a link may exist between the two. Thus, alongside problems with cognitive function and movement, people also experience visual hallucinations, mood swings and irritability. Medication to help treat the movement difficulties found in Parkinson's disease, such as tremor and stiffness of muscles, can unfortunately make the symptoms of dementia worse.

- ✔ **Multiple sclerosis:** In this disease, the outer coating of nerve cells, called myelin, is deficient in some parts of the nervous system, which means that messages carried by the nerves aren't transmitted as well as they should be and may not get through at all. If the nerves affected are in the cortex of the brain, which is where most of the 'clever' functions people perform are carried out, patients can develop cognitive symptoms including forgetfulness and difficulty with problem solving.
- ✔ **Normal pressure hydrocephalus:** The brain and spinal cord are surrounded by cerebrospinal fluid, which supplies nutrients and acts as a shock absorber to protect the nervous system from damage during trauma. People with hydrocephalus have too much of this fluid, and it begins to damage nerve cells because of the increased pressure. Normal pressure hydrocephalus usually begins to develop in people aged 55 to 60.

The damage that normal pressure hydrocephalus causes in the brain produces symptoms similar to those of dementia, accompanied by difficulties with walking and urinary incontinence. Treatment involves fitting a shunt in the brain to allow the fluid to drain. If the treatment is carried out early in the disease process, the success rate for resolving symptoms is at least 80 per cent.

- ✔ **Creutzfeldt–Jakob disease (CJD):** This fatal brain disease is, thankfully, rare. It has four types, the most well-known being variant Creutzfeldt–Jakob disease. This version of the disease is believed to be linked to bovine spongiform encephalopathy, better known as BSE or, in tabloid headlines, mad cow disease.

CJD is contagious and is transmitted by an infectious protein called a prion. Once inside the body, prions rapidly destroy brain tissue, leading to death within a year. Symptoms of this awful disease include dementia, unsteadiness, slurring of speech, loss of bladder control and blindness.

- ✔ **Huntington's disease:** Another of nature's most unpleasant diseases, Huntington's disease is hereditary and is caused by a defect on chromosome 4. If one parent has the disease, a couple's children have a 50:50 chance of inheriting the condition. Symptoms don't develop until middle age, but once they do the disease progresses relentlessly until death. Alongside dementia, sufferers develop jerking movements of their limbs and changes in mood and personality.

Hormonal and nutritional causes

The following conditions are generally not as devastating as the neurological conditions described in the preceding section. Many of the symptoms caused by these conditions are reversible with the correct treatment. Hormonal and nutritional causes of dementia include:

- ✔ **Addison's and Cushing's disease:** These conditions, named after the doctors who first discovered them, both affect the levels of a hormone called cortisol. In Addison's not enough cortisol is produced; in Cushing's too much. The knock-on effect of these altered cortisol levels is a corresponding upset in the levels of some of the minerals in the blood stream, most notably sodium and potassium, which leads to confusion. Thankfully, by treating the underlying cause, the confusion is reversible.
- ✔ **Diabetes:** One of the most common reasons for doctors seeing people who are acutely confused is that their blood sugar levels are either too low or too high. Neither situation is particularly good for people, but when their blood sugar is adjusted, their confusion quickly fades.
- ✔ **Thyroid disease:** Thyroxine is a hormone produced in the thyroid gland, which sits at the front of the neck. In simple terms, this hormone is involved in metabolism within the body: too much and everything in the body is in a rush (the heart races, diarrhoea develops and people become agitated); too little and everything slows down (pulse is slow, people gain weight, skin becomes dry, hair falls out and they can become constipated). Both an under- and over-active thyroid can cause confusion. In both cases, the confusion can again be reversed by treating the underlying cause.
- ✔ **Hyperparathyroidism:** The parathyroid glands are pea sized and sit just behind the thyroid gland in the neck. The hormone they produce – parathyroid hormone – is involved in controlling levels of calcium, phosphate and vitamin D. If the gland becomes overactive, levels of calcium in the blood shoot up. Too much calcium can affect personality and consciousness, cause disorientation and, if not corrected quickly enough, coma. Treatment is curative.
- ✔ **Vitamin B12 deficiency:** This vitamin, found in fish, poultry, eggs and dairy products, is absorbed in the gut during digestion with the help of a protein called intrinsic factor. Some people either don't make enough of this protein or have a condition that destroys it. As a result, they don't absorb vitamin B12. One of the roles of this vitamin is ensuring healthy nerve function. A lack can cause numbness and tingling in the hands and feet and, if significant, mood changes and poor memory. Treatment by injection of vitamin B12 avoids the problem of lack of stomach absorption and can improve symptoms.

Alcohol-related causes

Indulging in more than the advised levels of society's favourite drug more often than recommended will reveal it to be the poisonous substance it truly is. The effects on the body are wide-ranging and it can wreak havoc on a number of our internal organs, but it's the problems it can cause in the liver and brain that mimic dementia.

- ✔ **Cirrhosis:** Liver cells can be damaged by alcohol. The liver can also be affected by viruses such as hepatitis and an autoimmune condition in which the immune system, rather than an infection, attacks the body. Such damage stops the liver working as it should do, which, among other things, leads to the build-up of toxic waste products in the blood. When these toxins build up they can damage brain cells, leading to encephalopathy, which encompasses a collection of symptoms like confusion, poor memory, personality change and inappropriate behaviour. Occasionally, encephalopathy can be reversed by treating the liver damage, but it can prove fatal.
- ✔ **Korsakoff's syndrome:** Another condition named after the doctor who discovered it, Korsakoff's syndrome is most often seen in alcoholics in whom high alcohol intake stops the absorption of a B vitamin called thiamine. Thiamine is needed for normal nerve cell function, and insufficient levels commonly cause people to develop memory problems and changes in personality. This condition can be treated by quitting the booze and taking a thiamine supplement.

Infectious causes

Many infections can produce acute confusion, especially in the elderly. This confusion can be caused by the direct effect of viruses or bacteria on the brain, the toxins they produce in the blood stream, or the more general effects of infection on the body, from high temperature to dehydration. The most common infections that can cause confusion – or to give it its more glamorous-sounding, old-fashioned name, delirium – are

- ✔ Urinary tract infections such as cystitis (affecting the bladder) and pyelonephritis (affecting the kidneys)
- ✔ Chest infections, from bronchitis to full-on pneumonia
- ✔ Severe viral infections like influenza
- ✔ Infections that directly affect the brain, such as meningitis (which affects the meninges covering the central nervous system) or encephalitis (which affects brain cells)

Prescription medication causes

Although doctors try to follow the age-old dictum ‘first do no harm’, and medicines are designed to help people get better rather than make them worse, prescribing doesn’t always work as planned. We’re all different, and in an ideal world all treatment would be bespoke rather than off the peg.

However, we don’t live in an ideal world and so, despite doctors’ best efforts, their prescriptions may make people, especially older people, feel more unwell than before they collected their pills from the pharmacy. The following medicines can potentially make people acutely confused:

- ✓ Benzodiazepines such as diazepam (valium)
- ✓ Strong painkillers such as tramadol, codeine and morphine
- ✓ Steroids like prednisolone (often used for chronic bronchitis and arthritis)
- ✓ Anticonvulsants such as carbamazepine and phenytoin
- ✓ Anticholinergics, including some hay-fever tablets and medicines used to treat an over-active bladder (such as oxybutynin)