Diagnosing and treating Parkinson’s disease

The paragraphs in the draft are numbered for the purposes of consultation. The final version will not contain numbered paragraphs.

Understanding NICE
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About this information

1. This information describes the guidance that the National Institute for Health and Clinical Excellence (called NICE for short) has issued to the NHS on Parkinson’s disease. It is based on ‘Parkinson’s disease: diagnosis and management in primary and secondary care’ (NICE Clinical Guideline No. [XX]), which is a clinical guideline produced by NICE for doctors, nurses and others working in the NHS in England and Wales. Although this information has been written mainly for people with Parkinson’s disease, it may also be useful for family members, those who care for people with Parkinson’s disease and anyone interested in Parkinson’s disease or in healthcare in general.

Clinical guidelines

2. Clinical guidelines are recommendations for good practice. The recommendations in NICE guidelines are prepared by groups of health professionals, people representing the views of those who have or care for someone with the condition, and scientists. The groups look at the evidence available on the best way of treating or managing the condition and make recommendations based on this evidence.

What the recommendations cover

3. NICE clinical guidelines can look at different areas of diagnosis, treatment, care, self-help or a combination of these. The areas that a guideline covers depend on the topic. They are laid out in a document called the scope at the start of guideline development.

4. The recommendations in ‘Parkinson’s disease’ (NICE Clinical Guideline No. [XX]) cover:
   - the diagnosis of Parkinson’s disease and the regular checks you should have if you’re diagnosed as having it
Information for the public – draft for consultation

- the way you should receive information
- the medicines that can be used
- other ways of helping with symptoms
- how to care for people whose mental health is affected
- the care you should receive at the end of your life.

5. The guideline does not specifically look at:

- treatments that aren’t common (for example, treatments that are in development or are not yet proven such as foetal cell transplantation)
- other illnesses or health problems that can affect a person with Parkinson’s disease (except where treatment needs to be different for a person with Parkinson’s disease).

6. This booklet tells you about the NICE guideline on Parkinson’s disease. It doesn’t attempt to explain the disease or its treatments in detail. For suggestions of starting points to find out more, see page 22.

7. If you have questions about the specific treatments and options covered, talk to your doctor or nurse, or another health professional, depending on what it is you want to know.

**How guidelines are used in the NHS**

8. In general, health professionals in the NHS are expected to follow NICE’s clinical guidelines. But there will be times when the recommendations won’t be suitable for someone because of his or her specific medical condition, general health, wishes or a combination of these. If you think that the treatment or care you receive does not match the treatment or care described on the pages that follow, you should talk to your doctor, nurse or other health professional involved in your treatment.
9. You have the right to be fully informed and to share in making decisions about your healthcare, and the care you receive should take account of your individual needs.

About Parkinson’s disease

10. Parkinson’s disease happens because of an imbalance in chemical messengers, caused by the loss of cells in a part of the brain called the substantia nigra. These cells produce a chemical messenger called dopamine. Dopamine is involved in transmitting messages that control the muscles. Dopamine levels are closely linked with the levels of other chemicals in the brain, including another messenger called acetylcholine. The low levels of dopamine and changes in other chemicals including acetylcholine lead to the symptoms of Parkinson’s disease. At present, it is not known what causes the loss of dopamine-producing cells.

11. The three main symptoms of Parkinson’s disease are:

• slow movements – it becomes difficult to start to move or it takes longer to make movements (this is given the medical name bradykinesia)

• rigid or stiff muscles that can make some everyday tasks uncomfortable or difficult

• shaking, called tremor, in a part of the body when it’s not being used – this usually happens in a hand or arm at first.

12. Although Parkinson’s disease mainly affects movement, people may have other symptoms such as depression. But it is important to remember that Parkinson’s affects people differently and to different degrees and you may not experience all of the symptoms described.

13. The symptoms of Parkinson’s can also happen in people who don’t have the disease. At present, there isn’t a reliable test that tells whether a person has the disease or not. The diagnosis is usually
made by examining the person and from knowledge about the person’s previous health. The section on pages 6–9 describes the NICE guidance on diagnosing Parkinson’s disease.

The care and treatment you should receive

**Discussing your condition and getting information**

14. As a person with Parkinson’s disease, communication with healthcare professionals and the information you are given should help you to take part in discussions about your condition, and make choices about the treatment you have.

15. Healthcare professionals should give you information and explanations in a way that suit your individual needs at every stage of your care. This applies to the things healthcare professionals talk to you about and the information you’re given to take away. If your needs change because your symptoms change or get worse, the way that you’re given information should also change. It’s also important that you’re given the same information from all the people you see.

16. When they’re talking to you, your doctor and other health professionals should be honest and realistic about the future. But they should also explain that although there isn’t a treatment for Parkinson’s itself, the symptoms can be treated, and there is a lot of research going on to find an effective cure and new treatments. **It is important to try to maintain a positive attitude at all times.**

17. You should be given a full plan describing the care you will receive. This should be agreed with you and your family or carers and your healthcare professionals. You should also be given the name of someone in specialist services who you can contact.

18. Your family members or carers should also be given information about Parkinson’s disease and the support services that are
available. The arrangements for assessing the care that you need should also be explained.

19. People with Parkinson’s disease who drive should be told to inform the Driver and Vehicle Licensing Agency (DVLA) and their car insurer about their condition when they are diagnosed.

**Diagnosis**

20. If your doctor thinks you may have Parkinson’s disease, you should see a Parkinson’s specialist quickly, and before any treatment is started. How quickly you should see the specialist depends on whether you could be in the early stages of the disease or if it seems that you could be in the later stages. If it seems that you could have early Parkinson’s disease, you should see the specialist within 6 weeks. But if your symptoms and your medical history suggest that you could be in the later stages of the disease, you should usually see someone within 2 weeks.

21. Parkinson’s disease should be diagnosed according to a set of ‘rules’ or criteria that have been drawn up from research done on donated samples of brain tissue from people with Parkinson’s disease. These rules are known as the United Kingdom Parkinson’s Disease Society Brain Bank Criteria.

22. If you have tremor and your specialist isn’t sure whether it’s happening because you have Parkinson’s disease, you may be offered a special type of brain scan called a SPECT scan. The results from this scan can give more information about the causes of the tremor.

23. Parkinson’s specialists should be able to send people for this type of brain scan if the results are likely to be helpful.
Tests that are available as part of a clinical trial

24. Some other types of scan and test are sometimes used to give more information about what's causing a person's symptoms. Although you should not be offered these routinely, from time to time you may be invited to take part in a clinical trial and you may then be offered one or more of the following:

- PET scan
- volumetric MRI
- an objective smell test as loss of the sense of smell can be an early indicator of Parkinson's disease.

25. If your doctor talks to you about taking part in a clinical trial, he or she should explain the aim of the trial and what's involved before you decide if you want to take part.

Tests that shouldn't be used

26. Some tests shouldn't be used to confirm the diagnosis of Parkinson's disease in people with symptoms but may be helpful for other reasons. These are:

- magnetic resonance spectroscopy
- trying the medicines levodopa and apomorphine to see whether they help the symptoms (levodopa and apomorphine are medicines for Parkinson's disease).

27. One type of scan called structural MRI gives information about how a person’s brain looks (rather than how it’s working). This type of scan can help to pinpoint whether symptoms are happening because of damage in an area of the brain. Although structural MRI shouldn’t be used to diagnose Parkinson's disease, your specialist might offer you this test if he or she suspects there could be another cause of your symptoms.
Once a diagnosis has been made

28. If you’re diagnosed with Parkinson’s disease, your diagnosis should be reviewed regularly (every 6–12 months) by your specialist. If you develop new symptoms that don’t seem to be linked with Parkinson’s disease, your specialist should think about your diagnosis again.

General care

29. If you have Parkinson’s disease, a health professional should provide you with help in the areas listed below. You should have someone who:

- regularly checks how you are on your medicines, and makes changes if they’re needed
- is a point of contact and support for you and your family or carers, sometimes coming to see you at home
- gives you reliable information about Parkinson’s disease and its symptoms and treatments, and the wider issues that can affect people with the disease and their family and carers.

Often, it’s a Parkinson’s disease nurse specialist who does this. He or she is a nurse who has specialised in caring for people with Parkinson’s disease. He or she works closely with the doctors to provide care tailored to your needs.

Physiotherapy

30. You should be offered help from a physiotherapist and your need for support reviewed regularly by your doctor. Physiotherapists use exercises and other physical strategies to help people with their symptoms. The physiotherapy should aim to improve:

- balance and flexibility
- walking (if you have become unsteady on your feet)
• aerobic fitness (the sort of exercise that makes your heart stronger)
• movement
• how well you can do things for yourself (for example, how easily you get around, and how well you can carry out routine tasks).

Physiotherapists can also give you advice on staying safe at home.

**The Alexander Technique**

31. The Alexander Technique is a way of changing the way you move during everyday activities, and this has an effect on the way you think about things. If you have Parkinson’s disease, you may find the Alexander Technique helpful.

**Occupational therapy**

32. You should be offered help from an occupational therapist and your need for support reviewed regularly by your doctor. Occupational therapists look at ways of helping you to overcome the effects of your symptoms in your day-to-day life. He or she can show you different ways of doing things to make them easier, and can help you to adapt your home or workplace so it’s easier for you to do things.

Occupational therapy could help you to:

• carry on with your usual activities at work and in your home for longer
• carry on with your hobbies and other leisure activities for longer
• improve your mobility, or delay it from getting worse
• look after yourself if you are having trouble in managing (for example, finding ways to help you eat, drink, wash and dress yourself)
• ensure your house or place of work is safe and suitable for you
It can also help if you have specific needs because you sometimes become confused or distracted.

**Speech and language therapy**

33. You should be offered help from a speech and language therapist and your need for support reviewed regularly by your doctor. He or she can help by giving you exercises and strategies to help you communicate as clearly as possible. Therapists can also provide equipment if speaking unaided becomes too difficult. Speech and language therapy could help:

- make your voice louder and sound more natural
- you to talk in such a way that people are more likely to understand you
- make sure that you can be understood at all times (in the later stages you may need something to help, such as a voice amplifier, although there are different types of aid)
- to check that you are swallowing enough and that you’re doing it safely.

**Medical treatments**

**If you have early Parkinson’s disease**

34. There is not a medicine that is a suitable treatment for everyone in the early stages of Parkinson’s disease.

35. When your doctor discusses the options with you, he or she should explain the differences between the types of medicine and how each type might help you in the short and long term. Your doctor should also describe the drawbacks of each treatment. When deciding on which one to try, it’s important to think about the things that are important to you in your daily life, and your current symptoms and health. All this should be covered in your discussions with your doctor.
doctor. **Many people with Parkinson’s find it helpful to make a short list of points they want to discuss with their doctor.**

36. The box below [page x] shows the different types of medicine that can help with symptoms in the early stages of Parkinson’s disease. The ‘notes’ section describes some specific points that are made in the NICE guideline. If you have any questions about the different medicines, you should talk to your doctor.
### Medicines for early Parkinson’s disease

<table>
<thead>
<tr>
<th>Type of medicine</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Levodopa</strong>, which is the naturally occurring chemical that the brain changes into dopamine</td>
<td>People with Parkinson’s disease will eventually need levodopa, even if they start off on a different medicine. The dose given should be as low as possible. A type of levodopa called modified-release or long-acting levodopa should not be used to try to delay complications (such as involuntary movements) from starting. Modified-release levodopa is made in such a way that its effects should last for longer in the body than those of the normal levodopa.</td>
</tr>
<tr>
<td><strong>Dopamine agonists</strong>, which work like dopamine in the brain</td>
<td>If a person has side effects that mean the medicine cannot be given in a high enough dose to work well, then another medicine should be given instead. If a type of this medicine called an ‘ergot-derived dopamine agonist’ is used, the patient should have some blood tests and a chest X-ray before starting the treatment. These should also be done on a yearly basis whilst taking it. For this reason, it is often better not to use an ergot-derived medication.</td>
</tr>
<tr>
<td><strong>Monoamine oxidase B inhibitors</strong> (MAO-B inhibitors), which increase the time that dopamine stays in the brain</td>
<td>These are suitable for certain people only, and are not recommended as the first medicines to try.</td>
</tr>
<tr>
<td><strong>Beta-adrenergic antagonists</strong> (also known as beta-blockers), which block some types of nerve message and may help some types of tremor</td>
<td>These are not recommended as the first medicines to try because they don’t seem to work particularly well and can affect a person’s mental health. If they are used, it is generally in young people with severe tremor.</td>
</tr>
<tr>
<td><strong>Amantadine</strong>, which boosts the amount of dopamine in the brain</td>
<td>This is not recommended as the first medicine to try.</td>
</tr>
<tr>
<td><strong>Anticholinergic medicines</strong>, which reduce the effects of acetylcholine</td>
<td>These are not recommended as the first medicines to try because they don’t seem to work particularly well and can affect a person’s mental health. If they are used, it is generally in young people with severe tremor.</td>
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</table>
If you are in the later stages of Parkinson’s disease

37. A person in the later stages of Parkinson’s disease will often be taking levodopa. Other medicines may be needed to help boost the effects of the levodopa. Which type of medicine is most helpful for you will depend on your symptoms and the stage of your disease, and also your lifestyle and wishes. Your doctor should discuss all these things with you. He or she should explain the differences between the types of medicine and how each type might help you in the short and long term. Your doctor should also describe the drawbacks of each type. The box below [page x] shows the different types of medicine that can help with symptoms in the later stages of Parkinson’s disease. The ‘notes’ section describes some specific points that are made in the NICE guidance. If you have any questions about the different medicines, you should talk to your doctor. Because sudden changes in medicines used for Parkinson’s disease can cause problems (such as involuntary movements), people who have been admitted to hospital should have their medication adjusted by a specialist.
### Medicines for later Parkinson’s disease

<table>
<thead>
<tr>
<th>Type of medicine</th>
<th>Notes</th>
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<tbody>
<tr>
<td><strong>Modified-release or long-acting levodopa</strong>, which boosts the amount of dopamine in the brain</td>
<td>Modified-release levodopa is made in such a way that its effects should last for longer in the body than normal levodopa. It isn’t recommended as the first medicine to try.</td>
</tr>
<tr>
<td><strong>Dopamine agonists</strong>, which work like dopamine in the brain</td>
<td></td>
</tr>
<tr>
<td><strong>Monoamine oxidase B inhibitors</strong> (MAO-B inhibitors), which increase the time that the dopamine stays in the brain</td>
<td>These can be used to help cut down ‘off’ time, which is when a person suddenly goes from being able to move to being unable to move. This ‘on-off’ effect can happen in people who have had Parkinson's for quite a long time and who are taking levodopa. The person goes into ‘off’ as the effects of the levodopa wear off. If the COMT inhibitor called entacapone is used it should be a special preparation (the trade name for this is Stalevo). The COMT inhibitor called tolcapone can be used for people who have tried entacapone but have found that it hasn’t helped. If you have tolcapone you need to have fortnightly checks on your liver during the first year of treatment.</td>
</tr>
<tr>
<td><strong>Catechol-o-methyl transferase inhibitors</strong> (COMT inhibitors), which make the effects of levodopa last for longer in the body</td>
<td></td>
</tr>
<tr>
<td><strong>Amantadine</strong>, which boosts the amount of dopamine in the brain</td>
<td>This may help to reduce dyskinesia, (which is the medical name for abnormal or involuntary movements) if it’s affecting your ability to do things.</td>
</tr>
<tr>
<td><strong>Apomorphine</strong>, which works like dopamine</td>
<td>Apomorphine injections may be given from time to time to help cut down ‘off’ time (see COMT inhibitors above) and to help with dyskinesia (see above) if it’s affecting your ability to do things. If your symptoms are severe, you may be offered what’s known as a continuous subcutaneous infusion of apomorphine, where the medicine goes into your body through a tube under the skin. This should be set up in a specialist unit, but you should be able to be monitored at home</td>
</tr>
</tbody>
</table>
**Trying to protect the brain cells**

40. Because Parkinson’s disease is caused by a reduction in number of certain cells in the brain, there have been efforts to find medicines that protect the remaining brain cells. This is called neuroprotection or neuroprotective therapy. At the moment there is not enough evidence to justify taking medicines routinely for neuroprotection, although you may be offered one as part of a clinical trial (see box below [page x]). If your doctor talks to you about taking part in a clinical trial, he or she should explain the aim of the trial and what’s involved before you decide if you want to take part.

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**Medicines and neuroprotection**

You should not be offered the following medicines to try to protect your brain cells, though you may be offered one of the top three (shown below with a star) as part of a clinical trial.

- Co-enzyme Q₁₀ *
- Dopamine agonists *
- Monoamine oxidase B inhibitors *
- Vitamin E

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**Surgery**

41. The NICE guideline deals only with the type of surgery known as deep brain stimulation, in which electrical signals from a tiny implant in the brain help to stop or reduce a person’s symptoms.

42. This can be done in different areas of the brain, such as parts called the subthalamic nucleus and the globus pallidus. Depending on where the implant is put, the procedure is called ‘subthalamic stimulation’ or ‘pallidal stimulation’. Usually the signals from the
implant are sent to both sides of the brain to control symptoms affecting either side of the body.

43. At present it's not clear whether subthalamic stimulation is a more effective treatment than pallidal stimulation. When your doctor discusses the options with you, he or she should explain the differences between the surgical procedures and the possible benefits and drawbacks of each. When deciding on a procedure, it's important for you and your doctor to think about the things that are important to you in your daily life, and your current symptoms and health. All this should be covered in your discussions with your doctor.

44. For subthalamic or pallidal stimulation to be an option, you should meet all the following requirements. You should:

- have tried medicines for movement problems but not found them much help
- be fit and not have any other major health conditions
- find levodopa helps your symptoms
- have no current mental health problems such as depression, or dementia (which happens in some people with Parkinson’s disease, and causes symptoms such as memory loss and confusion).

45. Implantation into another part of the brain called the thalamus may be an option if your main symptom is severe tremor and subthalamic implantation isn't possible.

**Treating other symptoms**

46. People with Parkinson’s disease can develop other problems besides the main symptoms affecting movement.
**Depression**

47. You should be offered an antidepressant called a serotonin reuptake inhibitor (SSRI for short) if you have moderate to severe depression unless there’s a health reason why this might not be suitable for you.

**Psychotic symptoms**

48. Psychosis is the medical name for mental problems affecting a person’s ability to think, communicate, behave or to understand what’s real and what’s not (called hallucinations). If you have psychosis, you should have a thorough evaluation of your health to try to understand what may be triggering the psychosis. You should also be offered treatment as appropriate.

49. If it’s possible that one of your medicines for Parkinson’s might be causing your psychosis, your doctor should think about gradually reducing your dose until you don’t take that particular medicine anymore.

50. But if you’re only having mild psychotic symptoms and they aren’t causing you too many problems, you and your doctor may decide that the benefits of your Parkinson’s medicines outweigh the drawbacks of the psychotic symptoms. If this is the case, you and your doctor may decide not to change your medicines.

51. The side effects of many medicines for psychosis can worsen a person’s Parkinson’s symptoms. For this reason, medicines that would normally be used to help psychosis shouldn’t be prescribed for a person with Parkinson’s disease.

52. The medicine called clozapine can be used to help with psychotic symptoms, but if you take this your doctor has to register you with a monitoring scheme. This is because, in a minority of people, clozapine has a serious side effect called agranulocytosis. In agranulocytosis, the bone marrow stops making a certain type of blood cell or makes fewer of them. It’s important that this is picked up
early because the condition can be fatal. This is why you need to have regular blood tests if you’re taking clozapine.

Dementia

53. Up to one in five people with Parkinson’s disease have dementia, which can have symptoms such as memory loss, confusion and speech problems. A type of medicine called a cholinesterase inhibitor has worked well for some people with this type of dementia, but the medicine is not yet licensed for use in this way. The NICE guideline recommends that more research is done to find out which patients would benefit from this treatment.

Sleep problems

54. People with Parkinson’s disease sometimes have problems with their sleeping patterns. Some people may feel an overwhelming feeling that they need to sleep during the daytime. Another problem is what is known as nocturnal akinesia. This is the medical term used for when a person becomes less able or unable to move or turn in bed during the night.

55. If your sleeping patterns have changed, your healthcare professional should discuss this with you and take details of the problems you are having and how long it has been happening. They should also advise you on steps you can take to help you sleep better.

56. If your Parkinson’s disease makes you need to sleep in the daytime, you should be offered a medicine called modafinil, which works in the brain to make you feel more awake.

57. If you have nocturnal akinesia, switching to a modified-release or long-acting levodopa may be an option. Long-acting levodopa is made in such a way that its effects should last for longer in the body than the normal levodopa.
58. Healthcare professionals should look out for two other problems that are more common in people with Parkinson’s disease. One is called ‘restless legs syndrome’ where the person has uncomfortable sensations in the legs and feels an uncontrollable need to move them. This often happens when the person is resting and so can be a problem at night. The second is called REM sleep behaviour disorder, where the person may ‘act out’ their dreams and move and jerk a lot in their sleep. If you have either of these problems you should be given help for them.

59. People who may fall asleep suddenly should be advised not to drive. They should also be aware of ways in which this may affect their job, such as their safety if operating machinery. Healthcare professionals should adjust medication to stop this happening as much as possible.

Avoiding falls

60. The symptoms of Parkinson’s disease, such as stiffness in the muscles, can lead to problems with falls or the fear of falling.

61. NICE has issued some guidance on what to do when an older person falls and how to prevent falls. Healthcare professionals should follow this guidance whenever the problem applies to a person with Parkinson’s disease (see page 21 for details of the guidance).

Other problems

62. Parkinson’s disease can also cause other problems because the nerve messages get disturbed. If you have any of the following, your doctor should offer you treatment to help:

- feeling faint when you stand up because of low blood pressure
- problems passing urine
- difficulty swallowing
- constipation
• difficulties with sex (including problems getting or maintaining an erection)
• excessive sweating
• dribbling or drooling (where saliva builds up in the mouth and trickles down outside the mouth).

**Planning care at the advanced stage of Parkinson’s**

63. Your healthcare professionals should invite you to discuss the support and choices that are available and to plan together the care you want to receive when you are nearing the end of your life.

64. You should be put in touch with an appropriate person if you want to discuss the arrangements about your death or if you want to talk about how you feel about dying. Similarly, your family or carers should have access to this type of support.

**Where you can find more information**

65. If you need further information about any aspects of Parkinson’s disease or the care that you are receiving, ask your doctor, nurse or other member of your healthcare team. You can talk to them about the NICE guideline on Parkinson’s disease, or information in this booklet.

**If you want to read the other versions of this guideline**

66. [Note: the information in this paragraph and the next one will apply when the guideline is published] There are four versions of this guideline:

• this one
• the full guideline, which contains all the recommendations on Parkinson’s disease, details of how they were developed, and summaries of the evidence on which they were based
• a version called the NICE guideline, which lists all the recommendations on Parkinson’s disease

• the quick reference guide, which is a summary of the NICE guideline for health professionals

67. All versions of the guideline are available from the NICE website (www.nice.org.uk/CGXXX). Printed copies of this booklet and the quick reference guide are also available. Phone the NHS Response Line on 0870 1555 455 and quote N0XXX (quick reference guide), N0XXX (information for the public).

If you want more information about Parkinson’s disease

68. NHS Direct may be a good starting point for finding out more about Parkinson’s disease. You can call NHS Direct on 0845 46 47 or visit the website (www.nhsdirect.nhs.uk).

69. There may be support groups for people with Parkinson’s disease in your area. Your doctor or nurse should be able to give you more details. Information about local groups may also be available from NHS Direct or your local library or Citizens Advice Bureau.

If you want to know more about NICE

70. There is more about NICE and the way that the NICE guidelines are developed on the NICE website (www.nice.org.uk). You can download the booklet ‘The guideline development process – an overview for stakeholders, the public and the NHS’ from the website, or you can order a copy by phoning the NHS Response Line on 0870 1555 455 (quote reference number N0472).

71. At the NICE website you can also find information for the public about other guidance that may be relevant for people with Parkinson’s disease:
Information for the public – draft for consultation


NICE is in the process of developing the following guidance (details available from www.nice.org.uk):

- Dementia: management of dementia, including use of antipsychotic medication in older people. *NICE Clinical Guideline* (publication expected February 2007).

- Donepezil, rivastigmine, galantamine and memantine for the treatment of Alzheimer's disease (including a review of existing Guidance No. 19) *NICE Technology Appraisal* (publication expected TBC).

72. Information for the public can also be ordered from the NHS Response Line on 0870 1555 455. Quote N0XXX for the information on depression; N0XXX for the information on falls and N0XXX for the information on Alzheimer’s disease.