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Faculty of the Psychology of Older People

A Guide to Psychosocial Interventions in Early Stages of Dementia

Reinhard Guss and colleagues
Collated on behalf of the Faculty of the Psychology of Older People.
A collaboration of people living with dementia and the Dementia Workstream Expert Reference Group.

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A Guide to Psychosocial Interventions in Early Stages of Dementia

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Introduction

If you have recently received a diagnosis of dementia, you may want to know what support is available to you. Depending on your needs, there are a variety of treatments and interventions which can help you with coming to terms with your diagnosis and maintaining your well-being.

What is a Psychosocial Intervention?

A 'psychosocial intervention' is a broad term used to describe different ways to support people to overcome challenges and maintain good mental health. Psychosocial interventions do not involve the use of medication.

Psychosocial interventions are available to people who have received a diagnosis of dementia and their families. They are intended to help people to live well following diagnosis.

Psychosocial interventions can help with:

- coming to terms with a diagnosis of dementia
- maintaining your social life and relationships after diagnosis
- reducing stress and improving your mood, for example, if feeling worried, anxious, or depressed
- thinking and memory (cognitive function)
- living independently
- quality of life – maintaining health and happiness, and control over your life
- support for your partner and family

Deciding on the right psychosocial interventions for you depends on your needs and preferences.

We have outlined a list of different needs people may experience, and the psychosocial interventions that may be helpful in addressing these needs.

Psychosocial interventions are then described in alphabetical order from page 6 to 62.

What is my need?

General Information (and time to adjust)

Adjustment to diagnosis

Specialist information (rare or unusual dementia, non-typical problems)

Stress, anxiety or depression

Improving and maintaining cognitive functioning

Help for families and caregivers

Couples/families, relationships and communication

Maintaining Independence

Maintaining Quality of Life

Planning for the Future

Advance Care Planning

What is advance care planning?

Advance care planning is the process of discussing and then recording your future wishes and preferences for care and treatment. This record comes into effect if you lose mental capacity to make important decisions about your current or future care. It can include statements on how you wish to be treated at the end of your life.

Who is advance care planning for?

Anyone can start to plan for the future and think about their advance care plan. However, advance care planning is particularly important if you have been diagnosed with a long-term, life-changing, or life-limiting illness. It is recommended that you begin advance care planning if you have a diagnosis of dementia.

What does advance care planning involve?

Advance care planning involves discussing and recording your wishes and preferences, and making these known to nurses, doctors, and other family members. It includes anything that is important to you, no matter how trivial it seems. Advance care planning may include:

- an advance decision to refuse treatment. A legal document stating your feelings and beliefs about treatments, and your wishes to refuse specific treatment (e.g. resuscitation) or care in future should you lose mental capacity
- an advance statement of wishes and preferences. This is a summary of how you would like to be cared for in future
- setting up a Lasting Power of Attorney (LPA). This is a legal document naming the person or people whom you have chosen to speak for you, should you lose mental capacity to make certain decisions.

This care plan should be shared with the relevant people, such as family members and doctors. It is recommended that you seek advice from your GP and a solicitor in drafting an advance decision. Many people also see a solicitor to create an LPA.

When should I start advance care planning and how long does it take?

You choose when and if you want to record an advance care plan, but it is generally advised that you do so soon after finding out that you have a diagnosis of dementia. You can take time to think about your future care, and it is possible to update or change your advance care plan at any time you wish.

What benefits might I see from doing advance care planning?

Through advance care planning, you are documenting your preferences and wishes for future care. This should give you:

- some control over the future
- peace of mind
- help for your partner, family and professionals to act in your best interests when faced with decisions concerning your treatment, care or finances

What are the possible limitations to advance care planning?

Not all parts of your advance care plan will be legally binding.

Advance decision making requires you to plan for your care leading up to your death. This may be difficult for you, your partner and your family to talk about openly. You may need some time to come to terms with your diagnosis before you are able to make plans.

Some aspects of advance care planning might incur financial cost, as they require the involvement of legal professionals. You will also need to pay a fee to register a LPA.

Who can support me with advance care planning?

For your advance statement of wishes and preferences, you can discuss your plan with your partner and family, particularly if it involves them. You may have further questions about treatment and care and therefore you may want to speak to your GP or other health professionals before you make any decisions.

You may want to discuss the legal aspects of an advance care plan such as a LPA with a solicitor, who can guide you through the process.

As there are many aspects of advance care planning, you may want to speak to a number of professionals when making decisions about your future care, for example:

- wishes and preferences – family, friends, GP, carers, etc.
- health care decisions – to be made with the relevant professional
- advance decisions – doctor and solicitor
- LPA – discuss with your solicitor
- advice on advance care planning – most professionals, memory services, dementia advisor

Where can I find professional support with advance care planning?

Local charities, outreach workers from Age UK, dementia advisors, Alzheimer's Society, social services (social workers or case managers), and some memory services provide access to advance care planning. Your GP will also be able to direct you to someone who can help.

Where can I find more information on advance care planning?

There are a number of resources available on the internet.

NHS Choices has information on advance care planning, advance decision to refuse treatment and power of attorney:
http://www.nhs.uk/conditions/dementia-guide/pages/dementia-diagnosis-plan.aspx
http://www.nhs.uk/carersdirect/moneyandlegal/legal/pages/advancedecisions.aspx
http://www.nhs.uk/CarersDirect/moneyandlegal/legal/Pages/Powerofattorney.aspx

Alzheimer's Society factsheet 463 Advance decisions and advance statements:
www.alzheimers.org.uk/factsheet/463

Who approves/recommends advance care planning?

Advanced care planning is recommended by the British Psychological Society, The Royal College of Psychiatrists and the European Association for Palliative Care.

National Institute of Health and Care Excellence (NICE).

1.1.4.4 Ethics consent and advance decision making.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care.* NICE Clinical Guideline 42.

Available at: www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

4.2.14 Care Management – support with legal matters.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

European Association for Palliative Care. Standard 3.2. Anticipating progression of the disease, advance care planning is proactive. This implies it should start as soon as the diagnosis is made, when the patient can still be actively involved and patient preferences, values, needs and beliefs can be elicited.

EAPC (2013). Recommendations on palliative care and treatment of older people with Alzheimer's disease and other progressive dementias. *Palliative Medicine*, published online 4 July 2013. Retrieved 10 June 2014 from: http://www.eapcnet.eu/Corporate/AbouttheEAPC/EAPCpublications/EAPCrecommendations/tabid/1616/ctl/Details/ArticleID/612/mid/3090/Default.aspx

Animal-Assisted Therapy and pets

What is animal-assisted therapy?

In this guide, we describe animal-assisted therapy as a type of therapy involving structured encounters with animals with the purpose of improving well-being and quality of life. It can involve therapeutic encounters with a range of animals, such as dogs, animals, fish, and also toy animals and robot animals.

Animal-assisted therapy has specific goals and outcomes and is different from just owning a pet or being in contact with animals, which can also make you feel good.

Animal-assisted therapy as a term has been used to describe a number of different interventions. Pets-as-therapy (PAT) animals are an example of an animal-assisted activity, and are not regarded as animal-assisted therapy. Similarly, being provided with an animal for practical support such as a Dementia Dog, or a guide dog is not animal-assisted therapy.

Who is animal assisted-therapy for?

Anyone with a diagnosis of dementia, and also their family or carers.

What does animal-assisted therapy involve? How does it work?

There is a wide range of approaches involving animals which have therapeutic value. Some animal-assisted therapy involves contact with an animal in the company of a trained handler. The therapist will facilitate your interaction with the animal with a specific goal or outcome in mind, for example, motivating you to exercise or improving your communication skills or confidence.

Sometimes animals are used to improve your well-being through bonding and companionship, or to help you maintain independence.

How long does animal-assisted therapy take?

The type of animal-assisted therapy you choose will determine the duration of treatment. Some animal-assisted therapy may involve making a long-term commitment to having an animal stay with you. You will co-operatively decide with your therapist if this is the therapy for you and how long you will be involved with the animal.

The responsibility and time-frame of having a pet should be considered. It may be more feasible to have short-term interactions with animals, for example offering to look after pets for friends and family.

What benefits might I see from having animal-assisted therapy?

Animal-assisted therapy can help to reduce loneliness, and may help alleviate depression and anxiety, or encourage you to engage in physical activity, leisure, and relaxation. Some studies suggest have suggested that time spent with animals can reduce blood pressure. Research has also suggested that spending time with animals can encourage people to be sociable.

What are the possible limitations to animal-assisted therapy?

- You may be allergic to some animals.
- Hygiene must be taken into account when around animals.

Who can provide me with animal-assisted therapy?

Depending on the type of animal-assisted therapy, this should be provided by an individual with the correct level of qualifications and experience in handling animals in a therapeutic setting.

If you want to spend time with animals without a therapist, you may be interested in an animal-assisted activity (such as from a PAT animal) or be interested in taking on your own animal as a companion.

Where can I ask for animal-assisted therapy?

You can request advice on animal-assisted therapy from your dementia advisor. You can also ask for information on an animal-assisted therapy provider at your memory clinic.

Where can I find more information?

Ask for information on animal-assisted therapy from a professional at your memory clinic. There are several private providers of animal-assisted therapy advertised on the internet, however, many of these advertise actually offer activities called animal-assisted interventions which are not animal-assisted therapy.

If you are interested in animal-assisted activities, or animals as practical support for your memory rather than animal-assisted therapy, these websites might be useful to you:
Pets as therapy: www.petsastherapy.org
Information on dementia dogs: www.dementiadog.org

What is the evidence for animal-assisted therapy?

There is limited evidence for animal-assisted therapy available in research literature at present, however small studies have shown that spending time with animals can benefit people living with dementia.

Filan S.L. & Llewellyn-Jones R.H. (2006). Animal-assisted therapy for dementia: A review of the literature. *International Psychogeriatrics, 18*(4), 597–611.

Who approves/recommends animal-assisted therapy?

Animal-assisted therapy is recommended by the British Psychological Society and The Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE).

1.7.1.2 Interventions for non-cognitive symptoms and behaviour that challenges in people with dementia.

1.8.1.3 Interventions for comorbid emotional disorders in people with dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care.* NICE Clinical Guideline 42.

Available at: www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

6.7.1 People with dementia and their carers are made aware of other non-pharmacological interventions that they may wish to consider.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Assistive Technology: Advice and support

What is Assistive Technology: Advice and support?

'Assistive technology' refers to devices and technology which help make life easier for you, and help you to cope with the changes that can come with having a diagnosis of dementia. They can help you to maintain independence, keep you and your family safe, and enable you to stay connected with your loved ones and your community.

As there is a range of assistive technology available, it is sometimes helpful to have specialist advice to help you choose and operate assistive technology.

Who is Assistive Technology: Advice and support for?

If you want some advice on what kind of assistive technology devices may help you now or in the future, you may wish to discuss your needs with an occupational therapist, or a professional who knows about assistive technology. If you have recently purchased or been given a new piece of equipment, it may be helpful to have guidance or training in using this effectively.

What does Assistive Technology: Advice and support involve?

Primarily, advice and support with assistive technology will involve a discussion about your specific needs. During this discussion the aim will be to see what kind of equipment can be helpful to you specifically.

There is equipment and devices which can help you in the following areas:

- speaking, for example, communication aids
- doing things independently at home
- keeping safe when going out, for example, satellite navigation to help you find places, or GPS trackers to help others to find you
- memory, for example, a medication monitor or alarm which reminds you to take your medication. An electronic dosage system can ensure you take the right quantity
- socialising and staying connected with others, such as tablet computers or video conferencing systems to help you keep in touch
- preparing food and drink, such as alarms which automatically shut off your gas supply should your cooker be left on
- keeping you and your family safe in the home, for example, against falls, or by helping to regulate the temperature

There are many devices available and it may be difficult thinking about which device will be the right one for you. Any combination of devices can be used depending on your own needs, and personalised professional advice can help you decide what will help you the most.

How long does it take to receive advice and support with assistive technology?

You may need time to think about the specific aspects of your life in which technology may help you; for example, you may wish to have a device that helps you remember tasks or appointments. A professional can provide you with information on these devices directly during a consultation. You may want them to show you how to use your chosen device so

you get the most out of it. You may want to have several sessions of learning with a professional, particularly if you want your family or partner to understand how it works as well.

Leaflets may also be provided so that you can go through options at your own pace.

What benefits might I see from having advice and support with assistive technology?

Assistive technology is designed to provide safety, peace of mind and increased independence, while causing as little disruption to your daily life as possible.

What are the limitations of advice and support with assistive technology?

Assistive technology may involve a significant financial cost. You will also need to learn how to use certain types of equipment. It may not fit with your lifestyle and you may have to change your routines.

Who can provide advice and support with assistive technology?

Some occupational therapists or other health and social care professionals can talk to you about assistive technology and how you and your family can use it effectively. They can also advise you on financial assistance, as many devices come at a cost. For a small charge, some disability living centres will loan you equipment so that you 'try before you buy'.

Where can I ask for advice and support with assistive technology?

Depending on your specific need, you may want to talk to someone at your memory service or to your GP about a referral to a specialist who can help you with assistive technology.

Mental health professionals such as community psychiatric nurses and occupational therapists can provide information and discuss it with you. There are also leaflets on assistive technology in many memory services and GP surgeries.

There are a range of private and not-for-profit organisations that provide assistive technology.

Ask your Dementia Advisor, social services or memory service for details of local providers.

Where can I find more information on assistive technology for myself?

Alzheimer's Society factsheet 437 Assistive technology - devices to help with everyday living: www.alzheimers.org.uk/factsheet/437

There is an online tool with information on a wide range of assistive technologies: http://asksara.dlf.org.uk/

Who approves/recommends advice and support for assistive technology?

Assistive Technology with support and advice is recommended by the British Psychological Society and The Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE).

1.1.10.2 Environmental design for people with dementia.

1.2.1.1 Integrated health and social care.

1.5.1.1 Promoting and maintaining independence of people with dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care.* NICE Clinical Guideline 42.

Available at www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

6.4.2 The service provides access to psychosocial interventions for occupational and functional aspects of dementia.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Cognitive Behaviour Therapy for anxiety or depression

What is cognitive behaviour therapy?

Cognitive behaviour therapy is a term used to describe a number of talking therapies which are used to overcome emotional and psychological problems. Cognitive behavioural therapy is commonly used to treat stress, anxiety and depression.

The word 'cognitive' refers to thinking, reasoning and memory. Cognitive behaviour therapy is also known as CBT.

There are alternatives to cognitive behaviour therapy. Other similar therapies include behavioural activation, acceptance and commitment therapy, cognitive analytic therapy, and mindfulness-based cognitive behaviour therapy.

Who is cognitive behaviour therapy for?

You may want to try a talking therapy such as cognitive behaviour therapy if you are feeling particularly stressed, worried, anxious, low in mood or depressed.

What does cognitive behaviour therapy do? How does it work?

Cognitive behaviour therapy aims to give you new skills to overcome current life challenges. It aims to change ways of thinking that might be unhelpful. This may make it easier to deal with demanding situations or difficult emotions.

Cognitive behaviour therapy involves meeting regularly with a trained therapist who will help you to learn new skills and techniques which may make you feel better and improve your life. You will talk about your thoughts and feelings with your therapist and they will guide you through different ways of overcoming your problems.

How long does cognitive behaviour therapy take?

The number of therapy sessions you are offered will depend on your needs, for example, how you are experiencing your difficulties. The number of sessions you have will be cooperatively decided by you and your therapist.

What benefits might I see from having cognitive behaviour therapy?

Cognitive behaviour therapy aims to give you a better understanding of your ways of thinking, your emotions and your ways of coping with life situations. Through this understanding you may:

- learn new skills to cope with stress, anxiety and depression, and other related experiences
- feel better, less stressed, less anxious, happier
- be able to carry on with your life and feel more active

What are the possible limitations of cognitive behaviour therapy?

Cognitive behaviour therapy is only one type of talking therapy and you may find that it is not the right one for you. You may wish to consider other types of talking therapies such as counselling or psychotherapy (see page 25), life review therapy (see page 38), or stress and anxiety management (see page 62).

Who can provide cognitive behaviour therapy?

A therapist trained in cognitive behaviour therapy can provide you with cognitive behaviour therapy. This is available through NHS services, or private therapy services which you will have to pay for.

Where can I go to ask for cognitive behaviour therapy?

A referral for cognitive behaviour therapy can be made by your GP or through your memory service if you are feeling stressed, anxious, worried or depressed. You can refer yourself for cognitive behavioural therapy through your local IAPT provider.

Where can I find more information on cognitive behaviour therapy for myself?

There is information on cognitive behaviour therapy is widely available on the internet. The NHS has further information on its website.

NHS Choices – Types of talking therapy
http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/types-of-therapy.aspx

Alzheimer's Soicety Factsheet 445. Talking therapies (including counselling, psychotherapy and CBT): www.alzheimers.org.uk/factsheet/445

Bristish Association for Behavioral & Cogntive Psychotherapies (BABCP). You can find a registered therapist from this website: http://www.babcp.com

What is the evidence for cognitive behaviour therapy for anxiety and depression for people living with dementia?

There is evidence that psychological therapies including cognitive behaviour therapy reduce depression and anxiety for people living with dementia and mild cognitive impairment, as well as for family caregivers.

Orgeta, V., Qazi, A., Spector, A.E. & Orrell, M. (2014). Psychological treatments for depression and anxiety in dementia and mild cognitive impairment. *Cochrane Database Systematic Reviews, 22*(1), CD009125.

Sadek, S., Charlesworth, G., Orrell, M. & Spector, A. (2011). The development of a Cognitive Behavioural Therapy (CBT) manual: A pilot randomised control trial of CBT for anxiety in people with dementia anxiety. *International Psychogeriatrics, 23*, S383–S384.

Selwood, A., Johnston, K., Katona, C., Lyketsos, C. & Livingston, G. (2007). Systematic review of the effect of psychological interventions on family caregivers of people with dementia. *Journal of Affective Disorders, 101*, 75–89.

Sommerlad, A., Manela M., Cooper, C., Rapaport, P. & Livingston, G. (2014). START (StrAtegies for RelaTive) coping strategy for family carers of adults with dementia: Qualitative study of participants' views about the intervention. *British Medical Journal Open*. Retrieved from: http://bmjopen.bmj.com/content/4/6/e005273.full.

Who approves/recommends cognitive behaviour therapy?

Cognitive behaviour therapy is recommended by the British Psychological Society and The Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE). 1.8.1.2 Interventions for co-morbid emotional disorders in people with dementia. 1.11.2.5 Support and interventions for the carers of people with dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care.* NICE Clinical Guideline 42. Available at www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP). 6.3.1 People with dementia have access to interventions to address their emotional needs.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Cognitive Rehabilitation

What is cognitive rehabilitation?

Cognitive rehabilitation is an approach to managing the impact that dementia-related difficulties, such as problems with thinking and memory, can have on everyday life.

Who is cognitive rehabilitation for?

Cognitive rehabilitation is for people who have early-stage dementia. Many cognitive rehabilitation programmes involve families and carers.

What does cognitive rehabilitation do? How does it work?

Cognitive rehabilitation usually starts with identifying things you would like to improve on or manage better. This is done in discussion with a trained professional, leading to agreement about which goals to work on together. The professional will then work with you to devise ways of achieving the goals you have identified. A family member is usually involved as well. Cognitive rehabilitation can involve learning strategies for managing memory problems, or better ways of tackling everyday tasks. Sometimes people choose to learn something new, such as how to use a mobile phone or iPad, to help in everyday situations, or to resume activities they used to enjoy.

Cognitive rehabilitation is not about curing or reducing dementia-related difficulties with thinking and memory; rather it is about learning ways of compensating for these difficulties or managing them better.

How long does cognitive rehabilitation take?

The number of sessions of cognitive rehabilitation will depend on your needs, how much training and support you require, and the specific goals you have set yourself. It will involve practising techniques and skills in between sessions as well.

What benefits might I see from having cognitive rehabilitation?

Cognitive rehabilitation cannot cure memory problems, but it can help you to live well with them. It may improve aspects of your daily life.

What are the possible limitations of cognitive rehabilitation?

Cognitive rehabilitation will require effort from you, both during and outside of sessions. Because the focus is on tackling things that are causing you difficulty, the focus will often be on areas that are challenging for you rather than the things you do well. It often means trying new things or finding different ways of doing things, which may be unsettling initially.

Who can provide me with cognitive rehabilitation?

Cognitive rehabilitation can be undertaken by an occupational therapist, a clinical psychologist or a clinical neuropsychologist.

Where can I ask for cognitive rehabilitation?

If you want cognitive rehabilitation you will need to attend a specialist service for people with dementia, a memory service, a neuropsychology service, a stroke service or a service for people living with ABI (acquired brain injury).

You will need to talk to your GP first about a referral to these services. It may be possible to access cognitive rehabilitation privately.

You may be able to access cognitive rehabilitation through a clinical trial in your area; ask your local memory services if one is currently running.

Where can I find more information on cognitive rehabilitation?

Information can be found through your memory service, your GP, or your dementia advisor.

What is the evidence for cognitive rehabilitation?

Current evidence on the effectiveness of cognitive rehabilitation is promising, showing that cognitive rehabilitation is helpful when it is tailored to individual goals.

Bahar-Fuchs A, Clare L, Woods B. (2013). Cognitive training and cognitive rehabilitation for mild to moderate Alzheimer's disease and vascular dementia. *Cochrane Database of Systematic Reviews*, 2013, Issue 6. Art. No. CD003260.

Clare, L., Bayer, A., Burns, A., Corbett, A., Jones, R., Knapp, M., Kopelman, M., Kudlicka, A., Leroi, I., Oyebode, J., Pool, J., Woods, B. & Whitaker, R. (2013). Goal-oriented cognitive rehabilitation in early-stage dementia: Study protocol for a multi-centre single-blind randomised controlled trial (GREAT). *Trials, 14*, 152.

Clare, L., Evans, S., Parkinson, C., Woods, R.T. & Linden, D. (2011). Goal-setting in cognitive rehabilitation for people with early-stage Alzheimer's disease. *Clinical Gerontologist, 34*, 220–236.

Clare, L., Linden, D.E., Woods, R.T., Whitaker, R., Evans, S.J., Parkinson, C.H., van Paasschen, J., Nelis, S.M., Hoare, Z., Yuen, K.S. & Rugg, M.D. (2010). Goal-oriented cognitive rehabilitation for people with early-stage Alzheimer's disease: A single-blind randomised controlled trial of clinical efficacy. *American Journal of Geriatric Psychiatry, 18*, 928–939.

van Paasschen, J., Clare, L., Yuen, K., Woods, R.T, Evans, S., Parkinson, C., Rugg, M. & Linden, D. (2013). Cognitive rehabilitation changes memory-related brain activity in people with Alzheimer's disease. *Neurorehabilitation and Neural Repair, 27*, 448–459.

Kurz, A.F., Leucht, S. & Lautenschlager, N.T. (2011). The clinical significance of cognition focused interventions for cognitively impaired older adults: A systematic review of randomised controlled trials. *International Psychogeriatrics*, 1–12.

Who approves/recommends cognitive rehabilitation?

Cognitive Rehabilitation is recommended by the The Royal College of Psychiatrists.

Memory Service National Accreditation Programme (MSNAP).
6.2.3 Service provides support for the cognitive aspects of dementia.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Cognitive Stimulation Therapy and Maintenance Cognitive Stimulation Therapy

What is cognitive stimulation therapy?

Cognitive stimulation therapy (CST) is a group therapy that is used to help strengthen a person's communications skills, thinking and memory. CST groups run for a limited number of sessions. Maintenance cognitive stimulation therapy (MCST) groups continue indefinitely, and aim to maintain the benefits that CST groups provide.

Who is cognitive stimulation therapy for?

CST is for anyone who has a diagnosis of dementia, in mild to moderate stages. It may also be suitable to you if you have a diagnosis of Mild Cognitive Impairment (MCI)

What does cognitive stimulation therapy do? How does it work?

It is used to make the most of your skills and mental functions through exercises and activities. It is a fun social activity, with a different theme and activity each week. There are also elements that help you to focus on the present, for example discussing items in the newspapers, and having a group name and song.

A typical CST session lasts for one hour and may involve games, singing, reminiscence, sharing stories, chatting and discussions, current events, arts and crafts.

MCST, like CST, aims to help slow down cognitive decline. This treatment follows on from a course of CST. This treatment is used to maintain the benefits of CST. It is identical to CST but often runs for much longer.

Practitioners will work from a standardised manual on CST which means most programmes will be similar but not exactly the same.

How long does cognitive stimulation therapy take?

CST usually runs for 14 sessions and you usually attend one or two sessions per week. MCST runs for as long as it is useful to you.

What benefits might I see from having cognitive stimulation therapy?

There are several benefits of attending a CST group, and these are gained through active participation in the activities during the programme. These benefits include:

- improving your confidence, and the way you feel about your self and your memory
- improving your communication skills
- giving you ideas about and an opportunity to practice how to stay physically and mentally active
- giving you the opportunity to socialise and share with people in a similar situation
- improving your quality of life

What are the possible limitations of cognitive stimulation therapy?

CST is a group programme and so it may not suit everyone's taste. The programme usually requires you to be involved in a number of activities designed to be fun and stimulating, such as singing and group games. You will need to continue with doing the exercises you were doing in the programme to maintain the benefits. MCST is designed to do this, however it is not yet widely available.

Who can provide me with cognitive stimulation therapy?

Practitioners trained in CST, often occupational therapists, mental health nurses, care workers and support workers. Often CST is available through your memory services or local mental health services.

Where can I ask for cognitive stimulation therapy?

Your local memory service will advise when and where CST is available. You will need to ask your GP for a referral to a memory service if you are not currently accessing this service.

Where can I find more information on cognitive stimulation therapy?

Information on CST can be found on the internet: www.cstdementia.com

You can also find information on CST at your local memory service.

What is the evidence for cognitive stimulation therapy?

There are large studies evaluating the effectiveness of CST. Findings show a significant positive impact on language skills (naming, word-finding and comprehension).
An interview study suggests improvements in mood, confidence and concentration, and highlights the supportive nature of the group. One study found that longer-term MCST led to continuous benefits in these areas, and maintaining living well with dementia, over a six-month period.

Orrell M., Aguirre E., Spector A., Hoare Z., Streater A., Woods B. et al (2014). Maintenance Cognitive Stimulation Therapy (MCST) for dementia: A single-blind, multi-centre, randomised controlled trial of Maintenance CST vs. CST for dementia. *British Journal of Psychiatry, 204*(6), 454–461.

Spector, A., Gardner, C. & Orrell, M. (2011). The impact of Cognitive Stimulation Therapy groups on people with dementia: Views from participants, their carers and group facilitators. *Ageing & Mental Health, 15*(8), 945–949.

Spector, A., Orrell, M. & Woods, B. (2010). Cognitive Stimulation Therapy (CST): Effects on different areas of cognitive function for people with dementia. *International Journal of Geriatric Psychiatry, 25*(12), 1253–1258.

Spector, A., Thorgrimsen, L., Woods, B., Royan, L., Davies, S., Butterworth, M. & Orrell, M. (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: Randomised controlled trial. *British Journal of Psychiatry, 183*, 248–254.

Who approves/recommends cognitive stimulation therapy?

Cognitive stimulation therapy is recommended by the British Psychological Society and the Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE).

1.6.1.1 Interventions for cognitive symptoms and maintenance of function for people with dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care.* NICE Clinical Guideline 42. Available at: www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

6.2.1 People with dementia have access to a local programme of group cognitive stimulation therapy.

6.2.2 People who have participated in group cognitive stimulation therapy have access to a maintenance CST programme.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Cognitive Training

What is cognitive training?

Cognitive training ('brain training') involves training specific aspects of your memory and other thinking skills. This is usually through an exercise or a game on a computer, but regular pastimes such as crosswords and Sudoku would also count as cognitive training. Cognitive training is not as personally-tailored and has not proved to be as effective as cognitive rehabilitation (see page 18). It is widely available on the internet and gaming consoles as 'brain training'.

Who is cognitive training for?

Cognitive training is for anyone who wants to keep their brain active and enjoys brain training games and puzzles, including people living with dementia.

What does cognitive training involve? How does it work?

Cognitive training assumes that the brain is like a muscle and can benefit from regular exercise to stay healthy ('brain training'). It also assumes that if you have dementia, you can maintain your current level of functioning or slow down decline through training your brain.

Each exercise or game is designed to train specific functions of your brain, such as:

- memory for words
- logic and reasoning
- memory of pictures or images
- problem solving
- mathematics

How long does cognitive training take?

Cognitive training and brain training is meant to be a regular activity done continually, usually at least once a day for a sustained period of time.

What benefits might I see from having cognitive training?

You may see an improvement in the areas that you train. For example, if you are having difficulty remembering a list of numbers, you may see benefits in this area when doing an exercise to train you to remember numbers. In other words, you would not see an improvement in your general memory, but it may help you to be better at remembering a list of numbers.

What are the possible limitations of cognitive training?

- There may be a small financial cost to some forms of cognitive training.
- Cognitive training activities need to be continued to maintain the benefits.
- Cognitive training needs to be personally-tailored to your specific needs in order to have any noticeable effects.
- Any benefits are likely to be restricted to the area being trained in, not more widely transferable.

Who can provide you with cognitive training?

The exercises and games are usually self-administered, using the internet, books and computer programs. Memory service programs are available in some areas.

Where can I get cognitive training (or where can I get advice on cognitive training)?

There is an overlap in how professionals describe cognitive training and cognitive rehabilitation (see page 18). You will need to speak to a specialist professional with knowledge of dementia and cognitive training if you want advice and support in doing cognitive training for yourself. Some memory services may have programs set up to offer a form of cognitive training to you. You may be offered cognitive rehabilitation (see page 18) or cognitive stimulation therapy (see page 20) instead. You can do general 'brain training exercises' by accessing intellectually stimulating materials, such as crosswords and Sudoku which can be found in a variety of newspapers, magazines or booklets, and on electronic media.

Where can I find more information about cognitive training for myself?

You can find many sources claiming to offer brain training on the internet; however many of these will have limited effectiveness in terms of achieving your goals. If you are looking for ways of maintaining your thinking and memory, you may wish to seek advice from a professional at your memory service. You will need a referral from your GP to access your memory service if you are not accessing this already.

What is the evidence for cognitive training?

Yu et al. (2009), in a literature review, concluded that interventions that were more structured and focused were more effective overall.

Yu, F., Rose, K., Burgener, S., Cunningham, C., Buettner, L., Beattie, E., Bossen, A., Buckwalter, K., Fick, D., Fitzsimmons, S., Kolanowski, A., Specht, J., Richeson, N., Testad, I. & McKenzie, S. (2009). Cognitive training for early-stage Alzheimer's disease and dementia. *Journal of Gerontological Nursing, 35*(3), 23–29.

Bahar-Fuchs, A., Clare, L. & Woods, B. (2013). A Cochrane review, found no evidence to show wider improvement, but people get better at the tasks that they practice.

Bahar-Fuchs, A, Clare, L. & Woods, B. (2013). Cognitive training and cognitive rehabilitation for mild to moderate Alzheimer's disease and vascular dementia. *Cochrane Database of Systematic Reviews* 2013, Issue 6. Art. No. CD003260. doi: 10.1002/14651858.CD003260.pub2.

Who approves/recommends cognitive training?

Moniz-Cook and Manthorpe (2009) recommend an individualised form of cognitive training which is administered by a trained professional.

Moniz-Cook, E. & Manthorpe, J. (2009). *Early psychosocial interventions in dementia: Evidence-based practice.* London: Jessica Kingsley Publishers.

Counselling and Psychotherapy

What is counselling? What is psychotherapy?

Counselling and psychotherapy are two forms of 'talking therapy' which you would have if you wanted support with personal issues, such as if you were stressed, worried, anxious or depressed. They involve meeting with and sharing your problems with your therapist on an individual basis in a confidential setting. There are different types of counselling and psychotherapy to choose from. The therapist aims to help you understand your particular problems so that you can work to overcome or manage these differently.

Who is counselling and psychotherapy for?

Counselling and psychotherapy are for people who are struggling on a personal level with problems and feelings arising from a diagnosis and the effect of dementia on their lives and personal relationships.

What does counselling and psychotherapy involve? How does it work?

Counsellors and psychotherapists are there to listen to you and discuss problems and feelings with empathy. The purpose of these sessions is not usually to give advice, but to provide a safe space to talk and to help you to find insight and understanding into any problems you may be experiencing.

How long does counselling or psychotherapy take?

Depending on your specific needs, one or many sessions may be carried out. How long each client is seen for tends to be a joint decision between client and therapist. Some people may see their therapist for a short period of time, perhaps a few weeks. Other people may want to see their therapist or counsellor for a number of months or years. Longer term therapy is more likely to be available through the private sector.

What benefits might I see from having counselling or psychotherapy?

Counselling and psychotherapy can provide relief from psychological and emotional distress, and can help you to understand your problems more fully.

What are the possible limitations to counselling and psychotherapy?

Talking therapies can involve confronting difficult experiences and memories. Counselling and psychotherapy are not for everyone and there are alternative talking therapies available such as cognitive behaviour therapy (see page 15) or life review therapy (see page 38). Much of the effectiveness of talking therapies depends on your relationship with your therapist, and you may wish to try someone different if you find your therapist is not the right one for you.

Who can provide me with counselling and psychotherapy?

Therapy sessions are carried out by specifically trained counsellors and psychotherapists.

Where can I ask for counselling and psychotherapy?

You should ask your GP or your memory service for a referral for counselling and psychotherapy through the NHS. Counselling and psychotherapy can be provided by both the NHS and private organisations.

Where can I find more information about counselling and psychotherapy for myself?

Your local memory service or a health care professional may be able to provide more information on counselling and psychotherapy.

More information on 'talking therapies' can be found on the Alzheimer's Society website: http://www.alzheimers.org.uk/factsheet/445

NHS Choices – Types of talking therapy
http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/types-of-therapy.aspx

You can find out more about counselling and psychotherapy from the following websites. You can also find a list of accredited therapists from these websites if you want to pay for therapy privately.

British Association for Counselling and Psychotherapy (BACP): http://www.bacp.co.uk

British Psychoanalytic Council (BPC): http://www.bpc.org.uk

United Kingdom Council for Psychotherapy (UKCP): http://www.ukcp.org.uk

What is the evidence for counselling and psychotherapy?

There is evidence that psychological therapies including counselling and psychotherapy can help to reduce depression and anxiety.

Junaid, O. & Hegde, S. (2007). Supportive psychotherapy in dementia. *Advances in Psychiatric Treatment, 13*, 17–23. doi: 10.1192/apt.bp.105.002030.
This article explores the use of psychotherapy to help people adjust to changes and difficulties brought about by dementia, improving quality of life.

Lipinska, D. (2009). *Person-centred counselling for people with dementia: Making sense of self.* London: Jessica Kingsley Publishers.

Who approves/recommends counselling and psychotherapy?

Counselling and Psychotherapy are recommended by the British Psychological Society and The Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE).

1.8.1.2 Interventions for comorbid emotional disorders in people with dementia.

1.11.2.5 Support and interventions for the carers of people with dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care.* NICE Clinical Guideline 42.

Available at www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

6.3.1 People with dementia have access to interventions to address their emotional needs.

6.6.1 Carers for people with dementia are offered an assessment, and intervention/s if appropriate, for their emotional, psychological and social needs.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Creative Arts Therapies

What are creative arts therapies?

Creative arts therapies are a type of psychotherapy (see page 25 for counselling and psychotherapy) which use media such as painting, literature, sculpture and music (among others) as a focus for treatment. Creative arts therapies have a therapeutic focus and are different from general arts activities.

You may also be interested in looking at 'Music Therapy' on page 43 for more information on how music specifically can be used as part of an intervention.

Who are creative arts therapies for?

Creative arts therapies are for anyone with a diagnosis of dementia who feels that artistic expression can help with emotional difficulties and maintaining quality of life. This may be something you wish to consider if you do not feel talking therapies are right for you, or if you want an alternative to talking therapies.

What do creative arts therapies do? How do creative arts therapies work?

Creative arts therapies can take place individually or in groups, and usually involve the creation and/or discussion of art in a confidential, therapeutic environment. It allows expression of thoughts and emotions that are difficult to express using words alone. The therapist will help you understand your feelings and emotions through helping you to express them creatively.

How long do creative arts therapies take?

Sessions usually last between one and two hours. The number of sessions can be dependent on individual need and desire.

What benefits might I see from having creative arts therapies?

Creative arts therapies aim to help you overcome emotional problems. They may offer you the following:

- the opportunity to express emotions which are difficult to convey in words alone
- intellectual stimulation
- improving well-being and quality of life

What are the possible limitations to creative arts therapies?

Creative arts therapies require specifically trained therapists and may not be available in your area. They may also involve discussion of difficult emotions or life events.

Who can provide me with creative arts therapies?

Creative arts therapies require therapists specifically trained in a particular form of art therapy. While sessions involving creative arts can be offered by many different types of professional as interesting activities, art therapy specifically addresses deeper and more specific issues, hence requiring a specifically trained therapist.

Where can I ask for creative arts therapies?

Creative arts therapists can be found working within multi-disciplinary teams in hospitals, day centres, hospices, care homes, therapy centres and in private practice across the UK.

Where can I find more information about creative arts therapies for myself?

Your health care professional or memory service may be able to provide you with more information.

Arts 4 Dementia website: http://www.arts4dementia.org.uk/arts-therapies

Alzheimer's Society website: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=708&pageNumber=3

What is the evidence for creative arts therapies?

There are many subjective accounts about the benefits of having creative arts therapies, such as improved well-being; however, objective measures of benefits of this type of therapy have yet to be investigated fully.

Beard, R.L. (2012). Art therapies and dementia care: A systematic review. *Dementia, 11*, 633–656.

Urbas, S. (2009). Art therapy: Getting in touch with inner self and outside world. In E. Moniz-Cook & J. Manthorpe (Eds.), *Early psychosocial interventions in dementia: Evidence-based practice*. London: Jessica Kingsley Publishers.

Who approves/recommends creative art therapies?

Creative arts therapies are recommended by the Royal College of Psychiatrists.

Memory Service National Accreditation Programme (MSNAP).

6.7.1 People with dementia and their carers are made aware of other non-pharmacological interventions that they may wish to consider.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Support from Dementia Advisors

What is a dementia advisor?

A dementia advisor is there to provide you with ongoing support to live well with dementia – a single named person you can go to at any stage. This support is sometimes called case management.

Who is a dementia advisor for?

Dementia advisors are for anyone who is affected by dementia. They are primarily for people with dementia, but may also be available for relatives and caregivers of people with dementia.

What does a dementia advisor do?

They provide you with the information you need, when you need it, and will work with you to help you access what you want. They aim to help you live independently, access other services, maintain your well-being and keep control of your life. They can:

- meet with you in person to answer specific questions
- help you find the information that you need
- develop an individual plan for receiving information
- help you to navigate and access other services that you may require (in some areas the dementia advisor role is called a 'dementia navigator')

The dementia advisor aims to meet with you regularly, in line with your information plan.

How long do I see a dementia advisor for support?

Dementia advisors will be available to support you after a diagnosis of dementia and will meet you again as your needs change.

What benefits might I see from seeing a dementia advisor for support and advice?

Dementia advisors offer information for free. Research into the benefits of having a single point of contact for information is ongoing. However, the expected benefit of seeing a dementia advisor is the opportunity for support in getting the information you need. You are likely to receive information that is what you need and is current and up to date. The benefits of receiving information on your condition include increased confidence, reduced stress, and reduced uncertainty about the future.

What are the possible limitations of seeing a dementia advisor?

You may not have a dementia advisor in your area. To access a dementia advisor you will need a referral from your GP or another professional, or from your memory service.

Who are dementia advisors?

Dementia advisors are staff or well trained volunteers from organisations such as the Alzheimer's Society or AgeUK.

Where can I find support from a dementia advisor?

Dementia advisors are community-based and will visit you in your own home. Ask your local GP, memory assessment service, volunteer centre or a local dementia services provider such as Age UK for details on dementia advisors in your area.

Where can I find more information about dementia advisors for myself?

To access a dementia advisor you will need a referral from your GP or another professional, or from your memory service. You can read the Alzheimer's Society Factsheet about dementia advisors on the internet here:
http://alzheimers.org.uk/site/scripts/download_info.php?fileID=532

Who approves/recommends support from dementia advisors?

Support from a dementia advisor is recommended by the Royal College of Psychiatrists and the Department of Health.

Memory Service National Accreditation Programme (MSNAP).

4.2.11 Person is able to access a range of post-diagnostic supports and interventions – Dementia advisor and support services for patients and carers.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Department of Health, National Dementia Strategy: Objective 4: People will have access to care support and advice after diagnosis – People with dementia will have access to a dementia advisor who will help them throughout their care to find the right information, care support and advice.

Department of Health (2009). *Living well with dementia: A national dementia strategy.* London: Department of Health

Dementia/Memory Cafés

What is a dementia café or memory café?

Dementia cafés are informal meeting groups which are open for anyone affected by dementia to drop in when they like. They are places where people with dementia, families, volunteers and professionals can all meet together to share information and experiences and speak openly about dementia.

Who is a dementia café or memory café for?

Dementia cafés and memory cafés are groups for anyone who is interested in dementia or has been affected by dementia. They are also open to volunteers and professionals.

What goes on in a dementia café or memory café? How does it work?

Dementia cafés are organised in the community so that you can meet other people affected by dementia and talk informally over a cup of tea or coffee. They are an opportunity to find more information about dementia and meet others who are in a similar situation. Dementia cafés will be organised in a community setting on a regular basis. Sometimes the group will organise a speaker to talk about a subject of interest at these meetings. For example, advance care planning may be discussed at dementia cafés (see page 6 for Advance Care Planning section).

How long do you go to a dementia café or memory café for?

These groups operate on an informal drop-in basis, and you do not need to 'join up' to have membership. You can find out the dates of when each dementia café meeting will take place and choose which ones you would like to attend. You may continue to attend these groups for as long as you want.

What benefits might I see from using a dementia café?

The benefits of attending a dementia café are increased opportunities to meet other people as well as opportunities to gain more information and support. A dementia café aims to prevent you from becoming isolated from other people.

What are the possible limitations to using a dementia café or memory café?

Dementia cafés may not have the expertise to provide information on specific questions you may have.

Who provides dementia cafés or memory cafés?

Groups are often organised by voluntary sector organisations such as Age UK and Alzheimer's Society, among others. They are run by a staff member from these organisations.

Where can I access a dementia café? (How do I join these groups?)

Groups meet in your local community. Your local group meeting may be held in a town/village hall, place of worship, or community centre. Details of meetings may be available in your local paper, GP surgery or the internet (websites below). You may also be able to find details through memory services and Alzheimer's Society.

Where can I find more information about dementia cafés for myself?

NHS Choices (In 'where can I find more information?')
http://www.nhs.uk/conditions/dementia-guide/pages/dementia-activities.aspx

You can find a local memory café using this online directory:
http://www.memorycafes.org.uk/

These organisations will have information at hand on local opportunities:

Telephone numbers:
Age UK Advice service: 0800 169 6565
Alzheimer's Society: (helpline) 0300 222 11 22

Websites:
Alzheimer's Society: www.alzheimers.org.uk
Age UK: www.ageuk.org.uk
Dementia Web: www.dementiaweb.org.uk
Alzheimer Café: www.alzheimercafe.co.uk

What is the evidence for dementia cafés?

A book has been published summarising how and why the dementia café (here called an Alzheimer café) works. It includes anecdotes, interviews and comments on themes that are discussed at meetings. Qualitative research suggests that dementia cafés are useful as on-going supportive groups.

Jones, G. (2010). *The Alzheimer Café: Why it works*. Berks, UK: The Wide Spectrum Publications.

Thompson, A. (2006). Qualitative evaluation of an Alzheimer Café as an ongoing supportive group intervention. In B.M.L. Miesen & G.M.M. Jones (Eds.), *Care-giving in Dementia Vol 4*. (pp.291–312). London: Routledge.

Who approves/recommends dementia cafés?

Dementia cafés are recommended by the Royal College of Psychiatrists.

Memory Service National Accreditation Programme (MSNAP).

4.2.10 Person is able to access a range of post-diagnostic psychosocial interventions: Peer support/self-help groups, for example, befriending schemes, dementia cafés.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Family/Systemic Therapy

What is family therapy?

Family therapy and Systemic therapy are forms of psychotherapy which involve helping people who are in a close relationship with each other to understand each other and communicate their feelings and emotions to each other.

Who is family therapy for?

Family therapy is for people with dementia and their families. It is also useful for people who are experiencing difficulties in their relationships with other family members. It is useful when you and people close to you are finding it hard to resolve current issues on your own, and need a safe space to talk openly.

What does family therapy involve? How does it work?

You would attend a family therapy session with your family or anyone who was in a close relationship with you. Family therapy aims to improve understanding between people in close relationships and to help people to communicate their feelings with each other. Family therapy sessions are designed to provide you with a safe place to express yourself with your family and for them to communicate their feelings to you. The therapy will involve you and the people close to you talking openly about the current issues and feelings and listening to each other. The therapist can help you and your family to learn better ways of relating to each other and how you may be able to help each other during times of difficulty.

How long does family therapy take?

Family therapy is conducted over several sessions, depending on your needs. Often you will attend therapy sessions on a regular basis, for example, one to four times per month. If difficulties are more complex, you may need to attend therapy for a longer period of time.

What benefits might I see from having family therapy?

Family therapy may improve your close relationships through helping you and those close to you understand and come to terms with issues affecting you all. It may help to reduce conflict arising from negative ways of relating by helping you and those close to you to learn new ways of dealing with difficult issues together. Family therapy aims to improve your well-being and the well-being of those close to you.

What are the possible limitations of family therapy?

It may be difficult for you and your loved ones to meet together regularly in a therapeutic setting. Although you may want to attend therapy, those close to you may not feel that they are ready to do this or that they need family therapy. In addition, family therapy may lead to you and those close to you having to make difficult choices, which may resolve conflict but may not ultimately lead to a positive outcome for everyone.

Who can provide me with family therapy?

A family therapist or mental health professional with training in family therapy or systemic therapy would be able to offer you family therapy.

Where can I ask for family therapy?

Family therapy is a specialist service which will need a referral from your memory service or your psychiatrist.

Where can I find more information on family therapy for myself?

Association for Family Therapy and Systemic Practice – this website can give you helpful information and advice on family therapy and systemic practice.
http://www.aft.org.uk

If you want to access Family Therapy privately, you can also find a list of accredited family therapists and systemic psychotherapists on the AFT website.

NHS Choices – Types of talking therapy – If you are needing more information to help you select the right talking therapy for you, this NHS website can help you:
http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/types-of-therapy.aspx

What is the evidence for family therapy?

Studies have found that family therapy and systemic approaches are effective in helping people and their families cope with chronic and life changing illnesses, including dementia.

Carr, A. (2009). The effectiveness of family therapy and systemic interventions for adult focused problems. *Journal of Family Therapy, 31*, 46–74.

Richardson, C. (2005). Family therapy outcomes in a specialist psychological therapy service. *Context, the magazine for family therapy and systemic practice, special edition, grey matters: Ageing in the family,* 77, 46–48.

Who approves/recommends family therapy?

Family interventions are recommended by the British Psychological Society and The Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE).
1.11.2.5 Support and interventions for the carers of people with dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care.* NICE Clinical Guideline 42.
Available at: www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).
6.6.1 The service provides access to psychosocial interventions for carers of people with dementia.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Involvement Groups for people with dementia

What is an involvement group?

Involvement groups are an opportunity for people to help their local services and community. These groups meet regularly to discuss how improvements can be made in the community and in professional services in relation to dementia. People who use services are sometimes called service users, and the groups are sometimes therefore called service user involvement groups. Groups are run and organised in a variety of ways.

Who are involvement groups for?

Involvement groups are for people living with dementia who want to be involved in the development of better services and contribute to making their communities more dementia-friendly.

What does an involvement group do? How do involvement groups work?

People with a diagnosis of dementia meet on a regular basis. Some groups are self organised. Some involve family and some do not. Groups usually involve some social time as well as 'business' time.

How long do involvement groups take?

Service-user involvement groups are usually ongoing, and members can continue to attend meetings for as long as they wish.

What benefits might I see from joining an involvement group?

Involvement groups for people with dementia can provide many opportunities such as:

- meeting other people who have similar experiences to you
- involvement in work to improve professional services
- involvement in work to fight stigma and prejudice in local communities

Involvement groups can also improve your confidence and help you to develop new skills.

What are the possible limitations of involvement groups?

Depending on where your group likes to meet, you may need to arrange your own transport. Taking part in regular meetings and events as part of the group's work may mean committing considerable time and energy. There may not yet be a group set up in your area.

Involvement groups for people with dementia encourage people to get involved in improving service provision and community understanding. If you do not feel that this is something you would like to do, this type of group may not be for you.

Who provides involvement groups?

Involvement groups can be organised and led by a health care professional, but can also be run by group members themselves. Voluntary sector organisations, such as Dementia UK and Alzheimer's Society, also organise service user involvement groups.

Where can I join an involvement group?

Health care professionals, voluntary organisations and memory services can direct you towards any groups running in your area.

Where can I find more information about involvement groups for myself?

You can find out more about local involvement groups for people living with dementia by asking professionals in your memory service. The following websites may also have information on involvement groups.

Dementia Engagement and Empowerment Project (DEEP):
http://dementiavoices.org.uk/

Alzheimer's Society:
http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1040

Dementia Action Alliance (DAA):
http://www.dementiaaction.org.uk/

What is the evidence on involvement groups?

Current evidence suggests that 'focus groups' of people with dementia create a support network which enables people to voice opinions and discuss needs that they would otherwise be unable to. There is also some preliminary work surrounding involving people with dementia in research and in service provision in general.

Cheston, R., Bender, M. & Byatt, S. (2000). Involving people who have dementia in the evaluation of services: A review. *Journal of Mental Health, 9*(5), 471–479.

McKeown, J., Clarke, A., Ingleton, C. & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing, 19*, 1935–1943.

Who approves/recommends involvement groups?

There is growing evidence for involvement groups, however, as this is a newly emerging area of research, there is no formal recommendations for involvement groups at present.

Life Review Therapy

What is life review therapy?

Life review therapy is a type of talking therapy that is done one-to-one with a trained therapist, where you look back over your life. It aims to help you to understand your past from different perspectives. It is one of many types of talking therapy (see page 25 for counselling and psychotherapy, see page 15 for cognitive behaviour therapy).

Life review therapy is different from life story work (see page 40 for life Story work).

Who is life review therapy for?

This type of therapy can be useful to people finding it hard to come to terms with their situation in life, and those struggling with depression and feelings of anger or bitterness.

What does life review therapy involve? How does it work?

Sessions of life review therapy involve exploring your life with a trained therapist who assists in examining your own experiences and life events, and helps to find ways of feeling better about your own story. It can help to integrate your life, and bring a sense of continuity and connectedness.

How long does life review therapy take?

It usually takes between 16 and 20 sessions.

What benefits might I see from doing life review therapy?

Feeling better about yourself and your own life, and helping to come to terms with difficult times in life. It can help provide comfort and meaning to you and your family, and can decrease depression and anxiety. It can also allow you to focus on positive memories, and improve your overall emotional well-being, sense and purpose in life.

What are the possible limitations of life review therapy?

It can be emotional, and sometimes upsetting, to think about some past life events. You may want to consider creative arts therapies if you want an alternative to talking therapies (see page 28 for creative arts therapies, or page 43 for music therapy).

Who can provide me with life review therapy?

A trained specialised therapist, usually a clinical psychologist, can offer you life review therapy.

Where can I ask for life review therapy?

Life review therapy is usually provided by a specialist service, or a private therapy service (which you will need to pay for). You will usually talk to your GP about accessing life review therapy. Your GP can then refer you to a specialist mental health or memory service which can provide life review therapy to you.

Where can I find more information on life review therapy?

You can ask at your memory clinic about life review therapy. A referral for life review therapy will need to be made through your memory clinic to access a therapist.
If you are looking for a therapist, and don't mind paying for this privately, see the British Psychological Society website for a list of accredited therapists: www.bps.org.uk

What is the evidence for life review therapy?

Life review therapy is currently in the theoretical stages of development, and there is insufficient evidence to draw conclusions at present, but there is some interest in researching this further.

Korte, J., Bohlmeijer, E.T., Cappeliez, P., Smit, F. & Westerhof, G.J. (2012). Life review therapy for older adults with moderate depressive symptomatology: A pragmatic randomised controlled trial. *Psychological Medicine, 42*(6), 1163–1173.
This study found that people having life review therapy reduced depression and anxiety symptoms.

Webster, J. & Haight, . (2002). *Critical advances in reminiscence work*. New York: Springer Publishing. This book looks at how life review therapy and other forms of reminiscence can improve the quality of life for people with dementia.

Who approves/recommends life review therapy?

Life review therapy is an alternative form of talking therapy. It is not currently recommended as a choice of therapy (see page 25 counselling and psychotherapy, page 15 for cognitive behaviour therapy, and page 34 for family/systemic therapy) over other forms based on the current evidence available.

Life Story Work

What is life story work?

Life story work is a continuous process as our stories do not end. Whilst it involves looking back on the past and recording important personal events, it also involves looking forward to future hopes. It is usually done on a one-to-one basis with your partner, a family member or someone who can guide you through the process.

Who is life story work for?

Life story work is for anyone with a diagnosis of dementia to do alone, with their families or with a professional.

What does life story work involve? How does it work?

Life story work is the process of remembering and recording past events and memories so that a biography is created. It is used to help you remember past events and also to communicate and share these memories and future hopes with other people.

A life story book often contains photographs or pictures which can help to illustrate your memories and important moments. If preferred, the end product of life story work can also be in the form of a website, DVD or PowerPoint presentation, a brief timeline, tapestry, soundtrack or scrapbook.

How long does life story work take?

The length of time that this intervention takes varies from person to person, and can continue for as long as you like.

What benefits might I see from doing life story work?

- Creating a life history record can be an enjoyable experience and may involve other members of the family.
- It can help you to maintain good mental health and well-being.
- A life story may be used to help people think about your care in the future when it may be more difficult for you to communicate.
- Your family will also benefit from having a record of your life history so these stories and facts are never lost or forgotten.

Who can support me with life story work?

A trained health care professional, or anyone working closely with a person with a diagnosis of dementia, can provide this. A close friend or family member can also work with a person, on a more informal basis, to produce a life story.

Where can I ask about support with life story work?

Life story work can be provided by health care professionals who work closely with a person with dementia, and who know them well, as well as close friends and family.

Where can I find more information about life story work for myself?

You can find information about starting life story work for yourself through the following websites.

www.lifestorynetwork.org.uk

Alzheimer's Society website: www.alzheimers.org.uk/lifehistorybook

Alzheimer's society have a Factsheet on life history making:
Alzheimer's Society (2011). *Remembering together: Making a life history book.*

http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=855

You can ask for advice on making a life history book from a professional at your memory clinic.

What is the evidence for life story work?

There is a body of evidence suggesting that life story work increases your understanding of your past and present, giving you greater awareness of your preferences for care and allowing care to be more person-centred. Life story work can help by reinforcing your sense of identity. It can also help you communicate and connect with your family and professionals involved in your care.

Life story work can help reduce anxiety and increases well-being through engagement in meaningful activity, maintains sense of self, reduces depression and improves sense of belonging, promotes participatory care and improves relationships between staff and family carers in inpatient settings.

There is evidence that individual reminiscence work, such as the production of a life story, results in benefits to mood, well-being and aspects of cognitive function.

Clarke, A., Hanson, E. & Ross, H. (2003). Seeing the person behind the patient: enhancing the care of older people using a biographical approach. *Journal of Clinical Nursing, 12*(5), 697–706.

Kellett, U., Moyle, W., McAllister, M. et al. (2010). Life stories and biography: A means of connecting family and staff to people with dementia. *Journal of Clinical Nursing, 19*, 11–12, 1707–1715.

McKeown, J., Clarke, A., Ingleton, C. et al. (2010). The use of life story work with people with dementia to enhance person-centred care. *International Journal of Older People Nursing, 5*(2), 148–158.

McKeown, J., Clarke, A. & Repper, J. (2006). Life story work in health and social care: Systematic literature review. *Journal of Advanced Nursing, 55*(2), 237–247.

Moos, I. & Bjorn, A. (2006). Use of the life story in the institutional care of people with dementia: A review of intervention studies. *Ageing & Society, 26*(3), 431–454.

Sebern, M. & Whitlatch, C. (2007). Dyadic relationship scale: A measure of the impact of the provision and receipt of family care. *The Gerontologist, 47*(6), 741–751.

Thompson, R. (2011). Using life story work to enhance care. *Nursing Older People, 23*(8), 16–21.

Who approves/recommends life story work?

Life Story work is recommended by The Royal College of Psychiatrists.

Memory Service National Accreditation Programme (MSNAP).

6.1.1 The Service has access to a range of evidence-based psychosocial interventions.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Music Therapy

What is music therapy?

Music therapy describes interventions which aim to enhance your well-being and quality of life through the use of music and music-based therapeutic activity. This is a type of creative art therapy (see Creative Arts Therapies on page 28 for more information on these).

What does music therapy involve? How does it work?

A qualified music therapist will use a variety of specialist approaches to help you to explore your emotions. Music therapy can also be a part of reminiscence, helping to bring old memories to the surface. Sessions can be in groups or for individuals.

You can take part in music therapy groups which are fun, social activities that involve listening to and sharing music with others.

With your music therapist, you may use a variety of instruments, although one of the most common instruments used is your own voice.

Who is music therapy for?

Music therapy can be for anyone who feels that interaction with music can improve their well-being and quality of life. It is often used when someone finds it difficult to engage with a purely verbal therapy.

How long does music therapy take?

Sessions usually last for one or two hours and music therapy is often ongoing.

What benefits might I see from having music therapy?

By having music therapy, you may benefit from improved cognitive functioning, motor skills and quality of life, as well as an opportunity to express difficult emotions.

Music therapy can help people of all ages with a range of needs, often related to disability, illness or injury.

What are the limitations of music therapy?

Music therapy requires a specifically trained music therapist, and so may not be provided in your area.

Who can offer me music therapy?

Music therapy can be provided by trained music therapists and trained specialists.

Where can I ask for music therapy?

Music therapists can be found working within multi-disciplinary teams in hospitals, day centres, hospices, care homes, therapy centres and in private practice across the UK.
You usually need a referral to a specialist mental health or memory service from your GP to access music therapy.

Where can I find more information about music therapy for myself?

You can ask a professional at your memory service to provide more information on music therapy.

You can also find out more information from the following websites.

Alzheimer's Society website:
http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=134

Age UK website:
http://www.ageuk.org.uk/health-wellbeing/conditions-illnesses/dementia-and-music/

British Association for Music Therapy:
http://www.bamt.org

AgeUK:
http://www.ageuk.org.uk/health-well-being/conditions-illnesses/dementia-and-music/

What is the evidence for music therapy?

There is some evidence that the use of music therapy in dementia care is beneficial, though most research has been done only in the context of Alzheimer's disease. Individual studies with people with Alzheimer's disease found that recall for new information was improved when the information was presented in the context of song as opposed to spoken information, and MMSE (Mini-Mental State Examination, a measure of cognitive functioning) scores seemed to improve immediately following a music therapy intervention. Another study found that music therapy seemed to improve face-name recognition in short term and in longer term memory.

A 2004 Cochrane review found 10 small studies of music therapy with positive outcomes, but the generally poor quality of the studies meant that no significant conclusions could be drawn. There is also an overview of the use of music therapy in the context of Alzheimer's disease, as well as a book examining the use of music therapy in dementia care.

Aldridge, D. (Ed.) (2000). *Music therapy in dementia care*. London: Jessica Kingsley Publishers.

Carruth, E.L. (1997). The effects of singing and the spaced retrieval technique on improving face-name recognition in nursing home residents with memory loss. *Journal of Music Therapy, 34*, 148–164.

Guetin, S., Charras, K. & Berard, A. (2013). An overview of the use of music therapy in the context of Alzheimer's disease: A report of a French Expert group. *Dementia, 12*(5), 619–634.

Prickett, C.A. & Moore, R.S. (1991). The use of music to aid memory of Alzheimer's patients. *Journal of Music Therapy, 28*(2), 101–110.

Smith, G., (1986). A comparison of the effects of three treatment interventions on cognitive functioning of Alzheimer patients. *Music Therapy, 6A*(1), 41–56.

Vink, A.C., Bruinsma, M.S. & Scholten, R.J.P.M. (2004). Music therapy for people with dementia. *Cochrane Database of Systematic Reviews*, 2004, Issue 3. Art. No. CD003477.

Who approves/recommends music therapy?

Music therapy is recommended by the British Psychological Society and The Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE).

1.7.1.2 Interventions for non-cognitive symptoms and behaviour that challenges in people with dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care.* NICE Clinical Guideline 42.

Available at www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

6.7.1 The service provides information and signposting on other non-pharmacological interventions that the person with dementia and their carer may wish to consider.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Peer Support Groups

What is a peer support group?

Peer support groups are organised so that small groups of people who have been similarly affected by dementia can meet and support each other through sharing their experiences and thoughts.

Who are peer support groups for?

Peer support groups can be for people who have recently been diagnosed with dementia or are in the early stages of dementia. There are also groups for family members and caregivers which offer peer support. Some groups are designed for you to attend with your family.

What do peer support groups do? How do they work?

Group members can share what they find difficult and challenging and how they have overcome these challenges. Often just sharing a problem, or knowing someone else has felt the same, may make the problem feel more manageable. Group members can share information they have received or talk about the support that they have had.

How long does peer support take?

Groups meet for a set period of time, for example, once a week for six weeks. Depending on your group, you may meet for one or two hours during each session.

What benefits might I see from joining a peer support group?

You may feel differently about your own situation if you share this with people in a similar situation to you. This may lead to you feeling:

- increased confidence
- reduced depression
- increased quality of life

What are the limitations of peer support groups?

It is hoped that by joining a group you will be able to share your experiences with people who understand and have similar experiences. However, you may not feel like sharing your experiences at the moment. You may not feel the people in the group you join are similar to you at all. For instance, individuals under 65 with young onset dementia may not share the same problems with the majority of people attending these groups.

Who can provide peer support groups?

Groups are often led by a professional group facilitator. Professionals from a memory service are often involved in these groups.

Where can I ask to join a peer support group?

Groups are often referral only, which means you will have to be referred through your memory service in order to attend one.

Where can I find more information on peer support groups for myself?

Ask a professional at your memory assessment service about peer support groups available in your area.

You can also find details about peer support groups from the following website.
UK Dementia: http://www.dementiaweb.org.uk

What is the evidence for peer support groups?

There is evidence that peer support groups can improve quality of life, reduce depression and improve communication between family members.

Logsdon et al. (2010). Early-Stage Memory Loss Support Groups: Outcomes from a randomised controlled clinical trial. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 65B*(6): 691–697.

Who approves/recommends peer support groups?

Peer support groups for people living with dementia are recommended by The Royal College of Psychiatrists.

Memory Service National Accreditation Programme (MSNAP).

3.8.6 People with dementia and their carers are able to access post-diagnostic support groups.

4.2.1 The service provides or signposts and refers on to peer support group/self-help groups, for example, befriending schemes, memory café's.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Occupational Therapy

What is occupational therapy?

Occupational therapy is an approach which aims to improve your quality of life and maintain your well-being through doing everyday activities. Part of occupational therapy is enabling you to keep doing the activities that you enjoy. All occupational therapy should be personally tailored to your needs and circumstances and should involve working towards goals you agree with your occupational therapist.

Who is occupational therapy for?

Occupational therapy is aimed at anyone with a diagnosis of dementia and their carers who want support in improving their quality of life and maintaining their well-being.

What does occupational therapy involve? How does it work?

Occupational therapists help people maximise their abilities and overcome their disability through the use of meaningful occupation. They seek to maintain or improve an independent lifestyle and your well-being. They will want to know what is important to you and will work with you to find out ways to achieve your goals, independently and together with your family.

Occupational therapists can help you with the following:

- learn to do things in a different way
- install and use adaptations to live independently in your home
- help you to think about using your strengths

An example of this type of therapy is community occupational therapy for persons with dementia and family carers (CoTID). This involves individualised goal setting with the person with dementia and their carer.

How long does occupational therapy take?

Occupational therapy can take as long as you need to achieve your goals. You may wish to change your goals as your circumstances change, or modify them to overcome new challenges over the course of your treatment. You will plan how long you need with your occupational therapist during the course of your assessment.

What benefits might I see from occupational therapy?

- Increased independence at home.
- Increased engagement in activities that are purposeful and meaningful to you.
- Helping your family or carers to manage better with supporting you.
- Helping you maintain a healthy and meaningful lifestyle.

What are the possible limitations of occupational therapy?

It involves some level of commitment to a programme of intervention in order for it to be effective.

Who can provide me with occupational therapy?

A trained occupational therapist.

Where can I ask for occupational therapy?

You can ask for a referral for occupational therapy through your memory service. You can also access an occupational therapist privately.

Where can I find more information about occupational therapy for myself?

You can find out more information about occupational therapy from the College of Occupational Therapists (COT): www.cot.co.uk

A COT Occupational Therapy booklet is available to download from the COT website: http://www.cot.co.uk/sites/default/files/marketing_materials/public/Dementia-leaflet.pdf

What is the evidence for occupational therapy?

There is some evidence to suggest that occupational therapy can be beneficial for people with dementia.

Fratiglioni, L., Winblad, B. & Struass, E. (2007). Prevention of Alzheimer's disease and dementia: Major findings from the Kungsholmen project. *Physiology and Behaviour, 92*(1–2), 98–104.

Gitlin, L.N., Corcoran, M., Winter, L., Boyce, A. & Hauck, W.W. (2001). A randomised, controlled trial of a home environmental intervention: Effect on efficacy and upset in caregivers and on daily function of persons with dementia. *The Gerontologist, 41*(1), 4–14.

Graff, M.J., Vernooij-Dassen, M.J.M., Thijssen, M., Dekker, .J, Hoefnagels, W.H.L. & Olde Rikkert, M.G. (2006). Community-based occupational therapy for patients with dementia and their caregivers: A randomised controlled trial. *British Medical Journal, 333*(7580), 1196–1201.

Who approves/recommends occupational therapy?

Occupational therapy for dementia is recommended by the British Psychological Society and The Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE).

1.5.1.1 Promoting and maintaining independence of people with dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care.* NICE Clinical Guideline 42.
Available at www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

6.4.1 People have access to personally tailored occupational therapy to assist them with their occupational and functional needs and to help maintain their health and well-being, independence and community living.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Post-Diagnostic Counselling

What is post-diagnostic counselling?

Post-diagnostic counselling is a process of providing support with coming to terms with your diagnosis of dementia. It also involves thinking about your needs and working out the next steps in your treatment. It can involve individual sessions at your memory service, usually offered after a diagnosis to help discuss the diagnosis, answer questions and give information about further advice and support.

Who is post-diagnostic counselling for?

All people who have received a recent diagnosis of dementia should receive some form of post-diagnostic counselling if they want this, and when they are ready to talk.

What does post-diagnostic counselling involve? How does it work?

When you receive a diagnosis of dementia, health professionals will give you information, advice and support relevant to you. They can also give information, advice and support to your family during this time.

This type of support can include:

- information about your diagnosis of dementia
- time to talk about your diagnosis
- time to discuss further support and planning for the future
- counselling to help with the emotional side of receiving a diagnosis

How long does post-diagnostic counselling take?

Post-diagnostic counselling often involves one to three sessions, but the number of sessions can vary dependent on your need. You will then be told about further options.

What benefits might I see from having post-diagnostic counselling?

- A greater understanding of how your diagnosis may affect you and your family.
- The opportunity to obtain the information you need to know at that time.
- An opportunity to discuss any worries or fears, and to discuss plans for coping and support in future.

What are the possible limitations of post-diagnostic counselling?

The amount of support available for post-diagnostic counselling sessions may vary depending on your local area. When further post-diagnostic support is suggested, you may have to wait until the next group, or until therapy is being run.

Who can provide me with post-diagnostic counselling?

Often this is available from your psychiatrist and sometimes from a clinical psychologist, occupational therapist, mental health nurse or GP.

Where can I ask for post-diagnostic counselling?

Post-diagnostic counselling is an important part of the diagnostic process and should be offered at the time when you are given a diagnosis of dementia.

Where can I find more information on post-diagnostic counselling for myself?

Your GP or memory service staff can give you more information on available support.

What is the evidence for post-diagnostic counselling?

This book gives an overview of the factors that should be offered in post-diagnostic counselling, and explains how individual needs can still be met with limited resources.

Moniz-Cook, E. & Manthorpe, J. (Eds.) (2009). *Early psychosocial interventions in dementia: Evidence-based practice*. London: Jessica Kingsley Publishers.

Who approves/recommends post-diagnostic counselling?

Post-diagnostic counselling for dementia is recommended by the British Psychological Society and The Royal College of Psychiatrists

National Institute of Health and Care Excellence (NICE).

1.4.6.1 Addressing needs that arise from the diagnosis of dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. NICE Clinical Guideline 42.

Available at www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

3.8.5 People are given adequate opportunities to talk through the implications of their diagnosis with members of the team, immediately after and/or during the days after they receive a diagnosis.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Post-Diagnostic Groups/Courses

What is a post-diagnostic group or course?

Post-diagnostic groups are for people who have recently been given a diagnosis of dementia, and sometimes their families. The group will run for a set number of sessions with different speakers, or themes to discuss each week. They are sometimes called post-diagnostic support groups, memory groups or memory courses.

Who are post-diagnostic groups for?

Post-diagnostic groups are for anyone who has been diagnosed with dementia recently (and their families). If you have just found out that you have been diagnosed with dementia, you and your family may want to find out more information, and find out what you can do next. You may want to meet other people who are in a similar position.

What does a post-diagnostic group do? How do they work?

During a group or course, you will have the opportunity to learn and talk about many subjects to do with memory, including:

- understanding memory problems and dementia
- learning memory techniques and strategies
- coping with real-life situations
- talking to family, friends and others about memory problems and dementia
- adjusting to a diagnosis
- living well with dementia

Some groups also cover practical issues, providing information on other services available as well as legal issues and any benefits you might be entitled to.

How long do post-diagnostic groups take?

The length of a course or group will vary depending on what is provided in your area. A typical course will be four to twelve sessions, with one session per week for two hours.

What benefits might I see from joining a post-diagnostic group?

Post diagnostic groups can help you to:

- learn about your memory
- think about ways to manage your symptoms of dementia
- increase your confidence and well-being
- give you a sense of belonging and purpose
- feel more able to cope with a diagnosis
- meet other people in similar situations

What are the possible limitations of post-diagnostic groups?

Post-diagnostic groups and courses may not meet your specific needs and information may be of a more general nature. If you have a rarer type of dementia, or have been diagnosed with dementia in the early stages, some of your needs may be met through having specific specialist information (see page 60) or having post-diagnostic counselling (see page 50).

Who provides post-diagnostic groups?

Post-diagnostic groups/courses are usually run by professionals who have an interest and experience in working with people living with dementia. They can be run by dementia advisors, occupational therapists, nurses, psychologists and support workers. They are often run by professionals from your memory service.

Where do I go to join a post-diagnostic group?

Groups/courses are conducted in hospitals, your local memory service, or public venues such as community centres. After you have been given a diagnosis, you may be offered the opportunity to attend a group if a professional feels it may benefit you and your family. Groups provided by the NHS are generally specialist-run, time-limited and focused.

Where can I find more information on post-diagnostic groups?

You can find more information about post-diagnostic groups at your local memory service.

If you are a carer of someone living with dementia, see Alzheimer's Society – Carer Information and Support Programme: www.alzheimers.org.uk/crisp

What is the evidence for post-diagnostic groups?

There are several studies indicating that post-diagnostic groups can provide social, emotional and educational support, a sense of purpose, increased self-esteem and well-being, and a sense of belonging that comes from being part of a group of people in similar situations. One study focussed on the possible benefits that post-diagnostic courses have for carers. It found that people who are part of a group specifically aimed at the problems arising for carers of people with dementia had greater confidence, increased knowledge, and enhanced coping skills, and that they felt better prepared for the future.

Brooker, D. & Duce, L. (2000). Well-being and activity in dementia: A comparison of group reminiscence therapy, structured goal-directed group activity and unstructured time. *Ageing and Mental Health, 4*, 354–358.

Milne, A., Guss, R. & Russ, A. (2013). Psycho-educational support for relatives of people with a recent diagnosis of mild to moderate dementia: An evaluation of a 'Course for Carers'. *Dementia.*

Moniz-Cook, E. & Manthorpe, J. (Eds.) (2009). *Early psychosocial interventions in dementia: Evidence-based practice.* London: Jessica Kingsley Publishers.

Snow, K. (2010). Moving forward: Post-diagnostic groups for people with a mild dementia. *Faculty of the Psychology of Older People Newsletter, 111*, 59–63.

Snyder, L., Quayhagen, M.P., Shephard, S. & Bower, D. (1995). Supportive Seminar Groups: An intervention for early stage dementia patients. *The Gerontologist, 35*, 691–695.

Yale, R. (1995). *Developing support groups for individuals with early stage Alzheimer's disease.* York: The Maple Press Company.

Who approves/recommends post-diagnostic groups?

Post-diagnostic support groups are recommended by the British Psychological Society and The Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE).

1.4.6.2 Addressing needs that arise from the diagnosis of dementia.

1.11.2.2 Support and interventions for the carers of people with dementia.

1.11.2.3 Support and interventions for the carers of people with dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care.* NICE Clinical Guideline 42.

Available at www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

3.8.6 People and their carers are able to access post-diagnostic support groups.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Reminiscence

What is reminiscence?

Reminiscence is an activity which involves remembering and retelling past memories and events from your life, often aided by looking at materials from a particular time.
It is more general than, and different from, life story work (page 40) and life review therapy (page 38).

Who is reminiscence for?

Reminiscence is for anyone with a diagnosis of dementia.

What does reminisce do? How does reminiscence work?

Reminiscence is usually done in a group setting with people talking about their memories and listening to each other.

It gives people the chance to revisit familiar times and share common experiences with other people. Reminiscence often includes the use of general prompts such as photos, objects or music from those times.

Reminiscence focuses on using a person's preserved memories, rather than focusing on disability.

You may talk about the following themes during reminiscence sessions:

- childhood, school days, work life
- family and relationships, holidays and journeys
- historic events

Reminiscence aims to maintain good mental health and provide an enjoyable, social activity.

How long does reminiscence take?

Reminiscence can vary in the number of sessions, ranging from one or two to ongoing groups.

What benefits might I see from doing reminiscence?

Attending regular reminiscence sessions may give you the following benefits:

- improved cognitive function
- improved quality of life
- a better understanding of your identity

What are the possible limitations to reminiscence?

Unpleasant memories may be brought up, causing discomfort. A skilled facilitator would be able to work through this with you sensitively.

Who can support me with reminiscence?

Reminiscence can be carried out by a trained professional, usually in a group setting.

Where can I ask for reminiscence?

You may be referred for reminiscence by your memory service.

Where can I find more information about reminiscence for myself?

Information can be provided by health care professionals.

What is the evidence for reminiscence?

A Cochrane review (Woods et al., 2009) found that evidence in support of reminiscence for people with dementia was inconclusive. However, at a meta-analytical level, it was found that improvements were seen in cognition, mood and functional ability, as well as reductions in depressive symptoms in the person with dementia and stress in the carer.

Baines, Saxby and Elhert (1987) found improvement in cognitive and behavioural measures in people with moderate to severe dementia when group reminiscence activity followed reality orientating, compared to a control group which participated in reality orientation only.

Baines, S., Saxby, P., & Ehlert, K. (1987). Reality orientation and reminiscence therapy: A controlled cross-over study of elderly confused people. *The British Journal of Psychiatry, 151*, 222-231.

Goldwasser, Auerbach and Harkins (1987) found improvement in self-reported depression for subjects in a reminiscence group compared to a supportive therapy group, and a third 'control' group which received no treatment. The study found no significant differences in cognitive or behavioural measures.

Goldwasser, A., Auerbach, S.M. & Harkins, S.W. (1987). Cognitive, affective, and behavioural effects of reminiscence group therapy on demented elderly. *The International Journal of Aging & Human Development, 25*(3), 209–222.

Woods, B., Spector, A.E., Jones, C.A., Orrell, M. & Davies, S.P. (2005). Reminiscence therapy for dementia. *Cochrane Database of Systematic Reviews* 2005, Issue 2. Art. No. CD001120.

Who approves/recommends reminiscence?

Reminiscence is recommended by the British Psychological Society and The Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE).

1.8.1.3 Interventions for non-cognitive symptoms and behaviour that challenges in people with dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care.* NICE Clinical Guideline 42.
Available at www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

6.2.4 People with dementia and their carers have access to a group reminiscence programme.

6.3.1 People with dementia have access to interventions that address their emotional needs.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Signposting

What is signposting?

'Signposting' is when a health professional makes you aware of other services, provides you with information in the form of a leaflet or booklet, or tells you where you can obtain further information or support.

For example, you may wish to know about a specific psychosocial intervention, a professional can signpost the appropriate support and information for you – this means that they will provide you with the relevant information, how to access that treatment and may even refer you to another service or professional offering that treatment.

Who is signposting for?

Signposting, or being given helpful information, is for people who have just received a diagnosis of dementia and want more information on their condition, or information about available support, treatment or networks. Information is also available for families and caregivers.

What does signposting involve? How does signposting work?

Signposting can include information about useful websites, local groups and courses, and other support and services available to you in your area.

Professionals will try to give you the information you want for the questions you have at the time. Information should be available to you throughout your contact with professionals, and therefore signposting is an ongoing process.

Professionals will have information on how you can access other services, and often they can refer you to other services which will be able to provide you with the treatment or support you need.

How long does signposting take?

Most information can be given to you by the professional directly. You may be shown where you can get further information on specific topics. This is an ongoing process and you may find you want different kinds of information at different times.

What benefits might I see from having information signposted to me?

- The information sent to you can answer some of the many questions that you and your family about your condition and the support available to you.
- You and your family can read through leaflets, booklets and internet resources at your own pace. This may mean you can make better-informed decisions.
- Having more information may increase your confidence and decrease your stress, by reducing uncertainty and giving you answers to some of your questions. It may also prepare you to make the most of limited time in appointments with professionals.

What are the possible limitations of signposting?

There may not be any or enough information available in written form relating to your specific questions. Moreover, If you do not use a computer, some online information may be inaccessible to you. It is also crucial that a health professional directs you to the right information at the times that you need this. Being given too much information all at once may feel overwhelming. You may find more specific information as well as signposting through specialist information (see page 60) or post-diagnostic counselling (see page 50).

Who can signpost information to me?

A professional such as your care co-ordinator, dementia advisor, mental health nurse, occupational therapist or psychologist at the memory service can direct you towards useful information. Specialist help-lines, nationally and locally, also offer signposting.

Where can I ask for information to be signposted to me?

At your memory service there will be a range of written information available. Staff at your memory service will be able to direct you to information available on the internet.

Useful information can also be gained from your local dementia café.

An outreach worker from the Alzheimer's Society or from AgeUK, or a dementia advisor, will be able to give or direct you towards the information that you need.

Where can I find more information for myself?

You can get information for this through by talking to a professional at the memory service, or through a dementia advisor. You can also receive information through the voluntary sector, and organisations such as the Alzheimer's Society.

Telephone Numbers:

Alzheimer's Society National Dementia Helpline: 0300 222 1122

Age UK: 0800 169 6565

Internet/Websites:

Alzheimer's Society: http://www.alzheimers.org.uk

DementiaUK: http://www.dementiauk.org/

NHS Choices: http://www.nhs.uk/Pages/HomePage.aspx

What is the evidence for signposting?

There is some research evidence to suggest that services which provide information to people with dementia and or their caregivers in combination with other forms of support such as training or direct help to navigate the health system are helpful in maintaining quality of life and helping to reduce signs of poor mental health. An example of this type of service is the Age UK dementia advisor service.

Corbett, A., Stevens, J., Aarsland, D., Day, S., Moniz-Cook, E., Woods, R., Brooker, D. & Ballard, C. (2012). Systematic review of services providing information and/or advice to people with dementia and/or their caregivers. *Int J of Geriatric Psychiatry, 27*(6), 628–635.

Who approves/recommends signposting?

Signposting by services is recommended by the Royal College of Psychiatrists.

Memory Service National Accreditation Programme (MSNAP).

> 6.7.1 The service provides information and signposting to other possible non-pharmacological interventions that the person with dementia and their carer may wish to consider.
>
> 3.8 The memory service is able to offer appropriate support, advice and information to people with memory problems/dementia and their carers at the time of assessment and diagnosis, as needed.
>
> 6.5 The service provides or can signpost/refer people and their carers on to interventions for more complex needs, if required.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Specialist Information (rare and unusual dementia, non-typical problems)

What is meant by specialist information?

This is information given to you by a trained specialist such as a clinical psychologist, neurologist, occupational therapist or psychiatrist for older people which is tailored to your specific condition or symptoms. It is for people with less common forms of dementia.

Who is specialist information for?

People diagnosed with young-onset dementia, fronto-temporal dementia (FTD), posterior cortical atrophy (PCA), Lewy body dementia, Parkinson's disease dementia or any of the many rarer forms of dementia (i.e. other than Alzheimer's disease, vascular dementia or mixed dementia).

What does specialist information involve? How does it work?

This intervention involves an assessment period with a professional as well as discussing your experiences with you and your family. The professional will work with you to discuss ways to overcome specific problems, as well as finding ways to build on your strengths. You may be given information to better understand your specific condition and you may talk about practical ways to manage your symptoms. As well as answering specific questions about your condition, further advice on other services available can be discussed.

How long does specialist information take?

You will agree on how often you meet with a professional. The professional may meet you as and when you need specialist input.

What benefits might I see from having specialist information?

- Receiving specialist information which is tailored to your needs may be more useful than the generic information which has already been given to you.
- You will have the opportunity to talk about your specific experiences and discuss ways of overcoming these issues with the professional.
- Having this information may help you and your family to plan for the future.

What are the possible limitations of specialist information?

Talking about your condition and planning for the future with your family may be a difficult subject to face. This may be an emotionally difficult experience for you and you may wish to seek post-diagnostic counselling before or during this process.

Who can provide me with specialist information?

A professional at your memory service: a clinical psychologist, psychiatrist, neurologist, occupational therapist or mental health nurse. If you have a less common form of dementia, you may also benefit from joining a support group for people with that condition – see, for example, www.ucl.ac.uk/drc/support-groups

Where can I ask for specialist information?

This intervention should be available to you from your memory service following your diagnosis of an unusual type of dementia or specific non-typical problems.

Can I find specialist information for myself?

If you need more specific specialist information, when you have been given a diagnosis of dementia, you can talk to a member of your memory service about this.

Who approves/recommends specialist information?

Specific specialist information for rarer types of dementia is recommended by

The Royal College of Psychiatrists.

Memory Service National Accreditation Programme (MSNAP).

3.8.9 The service has access to specialist post-diagnostic counselling provided by an appropriately qualified professional for people with specific needs.

4.2. Professionals working within the memory service ensure that the person (and their carer, where appropriate) is able to access a range of post-diagnostic supports and interventions.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Stress/Anxiety Management

What is anxiety or stress management?

Anxiety management, sometimes called stress management, is an intervention which aims to help you with worry, stress and anxiety. One type of technique used in anxiety management is relaxation. Relaxation refers to techniques which you can learn to help you with stress, worry and anxiety. Cognitive behaviour therapy (CBT) is also often used to help people to manage overwhelming feelings of stress and anxiety (see page 15 for cognitive behaviour therapy).

Who is stress/anxiety management for?

For people with dementia who are also experiencing anxiety problems or panic, or who want to reduce stress which can cause anxiety.

What does stress/anxiety management involve? How does it work?

Anxiety or stress management includes:

- identifying factors in your life which contribute to stress and anxiety
- learning about lifestyle changes which can reduce stress and anxiety (such as cutting down on caffeine or increasing exercise)
- learning techniques which can help to prevent stress and anxiety (such as relaxation)
- learning techniques which can help you to better cope with stress and anxiety (such as breathing exercises)

Relaxation techniques are often used in anxiety management. These techniques involve doing something which promotes calmness and well-being.

Techniques for relaxation include:

- guided meditation
- yoga
- Tai-Chi
- applied relaxation
- breathing exercises
- exercise
- activities, for example, walking, gardening, music

You can join a relaxation group and learn helpful techniques along with other people.

One type of relaxation programme is called ‘Applied Relaxation’. The focus of these techniques is to learn to relax your muscles in situations which you find stressful so that you feel less anxious.

How long does stress/anxiety management take?

Anxiety management groups or individual treatments run for a set number of sessions, usually on a weekly basis. You will need to attend all the sessions in order to have the benefits.

What benefits might I see from having stress/anxiety management?

- Anxiety management should help you to understand the causes of anxiety, and recognise the nature of your anxiety.
- Reduce stress in your life and reduce anxiety in everyday situations.
- By learning relaxation techniques you can reduce your levels of tension.

What are the possible limitations of stress/anxiety management?

Anxiety management is usually a group approach. Whilst you may learn how to cope with anxiety in everyday situations, you may not learn how to apply this to specific situations in which you find it difficult to cope with anxiety. If this is the case individual cognitive behaviour therapy (see page 15) may be more useful to you.

Who can provide me with stress/anxiety management?

Anxiety management groups may be run through your local memory service, primary care counselling service, or through your local Improving Access to Psychological Therapies (IAPT) service. You can also learn about anxiety management through self-help guides.

A psychologist, occupational therapist or mental health nurse can teach you relaxation techniques, and some can be learned through reading books or listening to a CD that guides you through the steps.

Where can I ask for stress/anxiety management?

By speaking to your GP or a professional at the memory service. You will need a referral from a health professional to join these groups.

Where can I find more information on stress/anxiety management for myself?

Any health care professional, including your GP, can point you in the direction of a stress and anxiety management group/course. Books or CDs for self-learning techniques are often available in bookshops or libraries. The Reading Agency 'Reading Well – Books on Prescription' scheme recommends such self-help books, which should be available in your public library – see http://readingagency.org.uk/adults/quick-guides/reading-well

What is the evidence for stress/anxiety management?

There is a wide range of different stress management techniques. The evidence varies, and more high quality studies are needed particularly involving people with dementia.

Who approves/recommends stress/anxiety management?

Anxiety management and stress management are recommended by The Royal College of Psychiatrists.

Memory Service National Accreditation Programme (MSNAP).
6.1.1 Support for people and carers.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

References

Aldridge, D. (Ed.) (2000). *Music therapy in dementia care*. London: Jessica Kingsley Publishers.

Alzheimer's Society (2011). *Remembering together: Making a life history book*. Retrieved 23 September 2014 from: www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1434

Bahar-Fuchs, A., Clare, L. & Woods, B. (2013). Cognitive training and cognitive rehabilitation for mild to moderate Alzheimer's disease and vascular dementia. *Cochrane Database of Systematic Reviews* 2013, Issue 6. Art. No. CD003260. doi: 10.1002/14651858.CD003260.pub2.

Baines, S., Saxby, P. & Ehlert, K. (1987). Reality orientation and reminiscence therapy. A controlled cross-over study of elderly confused people. *The British Journal of Psychiatry, 151*, 222–2231. doi: 10.1192/bjp.151.2.222

Beard, R.L. (2012). Art therapies and dementia care: A systematic review. *Dementia, 11*, 633–656.

Brodaty, H., Green, A. & Koschera, A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society, 51*(5), 657–664.

Brooker, D. & Duce, L. (2000). Well-being and activity in dementia: A comparison of group reminiscence therapy, structured goal-directed group activity and unstructured time. *Ageing and Mental Health, 4*, 354–358.

Bruce, E., Hodgson, S. & Schweitzer, P. (1999). *Reminiscing with people with dementia: A handbook for carers*. London: Age Exchange.

Bruce, E. & Schweitzer, P. (2008). Working with life history. In M. Downs & B. Bowers (Eds.), *Excellence in dementia care: Research into practice* (pp.168–186). Maidenhead: Open University Press.

Carruth, E.L. (1997). The effects of singing and the spaced retrieval technique on improving face-name recognition in nursing home residents with memory loss. *Journal of Music Therapy, 34*, 148–164.

Cheston, R., Bender, M. & Byatt, S. (2000). Involving people who have dementia in the evaluation of services: A review. *Journal of Mental Health, 9*(5), 471–479.

Clare, L. (2010). Goal-oriented cognitive rehabilitation for people with early stage Alzheimer disease: A single-blind randomised controlled trial of clinical efficacy. *American Journal of Geriatric Psychiatry, 18*, 928–939.

Clare, L., Bayer, A., Burns, A., Corbett, A., Jones, R., Knapp, M. et al. (2013). Goal-oriented cognitive rehabilitation in early-stage dementia: Study protocol for a multi-centre single-blind randomised controlled trial (GREAT). *Trials, 14*, 152.

Clare, L., Evans, S., Parkinson, C., Woods, R.T. & Linden, D. (2011). Goal-setting in cognitive rehabilitation for people with early-stage Alzheimer's disease. *Clinical Gerontologist, 34*, 220–236.

Clare, L., Linden, D.E., Woods, R.T., Whitaker, R., Evans, S.J., Parkinson, C.H. et al. (2010). Goal-oriented cognitive rehabilitation for people with early-stage Alzheimer's disease: A single-blind randomised controlled trial of clinical efficacy. *American Journal of Geriatric Psychiatry, 18*, 928–939.

Clarke, A., Hanson, E. & Ross, H. (2003). Seeing the person behind the patient: Enhancing the care of older people using a biographical approach. *Journal of Clinical Nursing, 12*(5), 697–706.

Corbett, A., Stevens, J., Aarsland, D., Day, S., Moniz-Cook, E., Woods, R. et al. (2012). Systematic review of services providing information and/or advice to people with dementia and/or their caregivers. *International Journal of Geriatric Psychiatry, 27*(6), 628–635.

EAPC (2013). Recommendations on palliative care and treatment of older people with Alzheimer's disease and other progressive dementias. *Palliative Medicine*, published online 4 July 2013, retrieved 10 June 2014 from http://www.eapcnet.eu/Corporate/AbouttheEAPC/EAPCpublications/EAPC recommendations/tabid/1616/ctl/Details/ArticleID/612/mid/3090/Default.aspx

Filan S.L. & Llewellyn-Jones R.H. (2006). Animal-assisted therapy for dementia: A review of the literature. *International Psychogeriatrics, 18*(4), 597–611.

Fogle, B. (Ed.) (1981). *Interrelations between people and pets.* Springfield, IL: Charles C. Thomas.

Fratiglioni, L., Winblad, B. & Struass, E. (2007). Prevention of Alzheimer's disease and dementia: Major findings from the Kungsholmen project. *Physiology and Behaviour, 92*(1–2), 98–104

Godwin, K.M., Mills, W.L., Anderson, J.A. & Kunik, M.E. (2013). Technology-driven interventions for caregivers of persons with dementia: A systematic review. *American Journal of Alzheimer's Disease and Other Dementias, 28*(3), 216–222.

Goldwasser, A., Auerbach, S.M. & Harkins, S.W. (1987). Cognitive, affective, and behavioral effects of reminiscence group therapy on demented elderly. *The International Journal of Aging and Human Development, 25*(3), 209–222.

Graff, M.J.L., Vernooij-Dassen, M.J.M., Thijssen, M., Dekker, J., Hoefnagels, W.H.L. & Olde Rikkert, M.G.M. (2006). Community-based occupational therapy for patients with dementia and their caregivers: A randomised controlled trial. *British Medical Journal, 333*(7580), 1196–1201.

Gitlin, L.N., Corcoran, M., Winter, L., Boyce, A. & Hauck, W.W. (2001). A randomised, controlled trial of a home environmental intervention: Effect on efficacy and upset in caregivers and on daily function of persons with dementia. *The Gerontologist, 41*(1), 4–14.

Guetin, S., Charras, K. & Berard, A. (2013). An overview of the use of music therapy in the context of Alzheimer's disease: A report of a French expert group. *Dementia, 12*(5), 619–634.

Hansebo, G. & Kihlgren, M. (2000). Patient life stories and current situation as told by carers in nursing home wards. *Clinical Nursing Research, 9*(3), 260–279.

Jones, G.M.M. (2010). *The Alzheimer Café: Why it works.* Berks, UK: The Wide Spectrum Publications.

Junaid, O. & Hegde, S. (2007). Supportive psychotherapy in dementia. *Advances in Psychiatric Treatment, 13*, 17–23.

Kellett, U., Moyle, W., McAllister, M., King, C. & Gallagher, F. (2010). Life stories and biography: A means of connecting family and staff to people with dementia. *Journal of Clinical Nursing, 19*(11–12), 1707–1715.

Korte, J., Bohlmeijer, E.T., Cappeliez, P., Smit, F. & Westerhof, G.J. (2012). Life review therapy for older adults with moderate depressive symptomatology: A pragmatic randomised controlled trial. *Psychological Medicine, 42*(6), 1163–1173.

Kurz, A.F., Leucht, S. & Lautenschlager, N.T. (2011). The clinical significance of cognition-focused interventions for cognitively impaired older adults: A systematic review of randomised controlled trials. *International Psychogeriatrics, 23*(9), 1364–1375.

Lipinska, D. (2009). *Person-centred counselling for people with dementia: Making sense of self.* London: Jessica Kingsley Publishers.

Logsdon, R.G., Pike, K.C., McCurry, S.M., Hunter, P., Maher, J., Snyder, L. et al. (2010). Early-stage memory loss support groups: Outcomes from a randomised controlled clinical trial. *Journal of Gerontology: Psychological Sciences, 65B*(6), 691–697.

McKeown, J., Clarke, A., Ingleton, C., Ryan, T. & Repper, J. (2010). The use of life story work with people with dementia to enhance person-centred care. *International Journal of Older People Nursing. 5*(2), 148–158.

McKeown, J., Clarke, A., Ingleton, C. & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing, 19*(13–14), 1935–1943.

McKeown, J., Clarke, A. & Repper, J. (2006). Life story work in health and social care: Systematic literature review. *Journal of Advanced Nursing, 55*(2), 237–247.

Milne, A., Guss, R. & Russ, A. (2013). Psycho-educational support for relatives of people with a recent diagnosis of mild to moderate dementia: An evaluation of a 'Course for Carers'. *Dementia.*

Moniz-Cook, E. & Manthorpe, J. (2009). *Early psychosocial interventions in dementia: Evidence-based practice.* London: Jessica Kingsley Publishers.

Moos, I. & Bjorn, A. (2006). Use of the life story in the institutional care of people with dementia: A review of intervention studies. *Ageing and Society, 26*(3), 431–454.

Murphy, C. (2000). *Crackin' lives: An evaluation of a life story book project to assist patients from a long-stay psychiatric hospital in their move to community care situations.* Stirling: Dementia Services Development Centre.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care.* NICE Clinical Guideline 42. Available at: www.nice.org.uk/CG42 [NICE guideline]

Orrell, M., Aguirre, E., Spector, A., Hoare, Z., Streater, A., Woods, B., et al. (2014). Maintenance Cognitive Stimulation Therapy for dementia: A single-blind, multi-centre, randomised controlled trial of Maintenance CST vs. CST for dementia. *British Journal of Psychiatry, 204*, 454–461.

Orgeta, V., Qazi, A., Spector, A.E. & Orrell, M. (2014). Psychological treatments for depression and anxiety in dementia and mild cognitive impairment. *Cochrane Database of Systematic Reviews* 2014, Issue 22. Art. No. CD009125

Prickett, C.A. & Moore, R.S. (1991). The use of music to aid memory of Alzheimer's patients. *Journal of Music Therapy, 28*(2), 101–110.

Richardson, C. (2005). Family therapy outcomes in a specialist psychological therapy service. *Context: the magazine for family therapy and systemic practice in the UK, 77*, 46–48.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Sadek, S., Charlesworth, G., Orrell, M. & Spector, A. (2011). The development of a Cognitive Behavioural Therapy (CBT) manual: A pilot randomised control trial of CBT for anxiety in people with dementia anxiety. *International Psychogeriatrics, 23*(S1), S383–S384.

Sebern, M.D. & Whitlatch, C.J. (2007). Dyadic relationship scale: A measure of the impact of the provision and receipt of family care. *The Gerontologist, 47*(6), 741–751.

Selwood, A., Johnston, K., Katona, C., Lyketsos, C. & Livingston, G. (2007). Systematic review of the effect of psychological interventions on family caregivers of people with dementia. *Journal of Affective Disorders, 101*, 75–89.

Smith, G. (1986). A comparison of the effects of three treatment interventions on cognitive functioning of Alzheimer patients. *Music Therapy, 6*(1), 41–56.

Snow, K. (2010). Moving forward: Post-diagnostic groups for people with a mild dementia. *Faculty of the Psychology of Older People Newsletter, 111*, 59–63.

Snyder, L., Quayhagen, M.P., Shephard, S. & Bower, D. (1995). Supportive seminar groups: An intervention for early stage dementia patients. *The Gerontologist, 35*(5), 691–695.

Spector, A., Gardner, C. & Orrell, M. (2011). The impact of Cognitive Stimulation Therapy groups on people with dementia: Views from participants, their carers and group facilitators. *Ageing and Mental Health, 15*(8), 945–949.

Spector, A., Orrell, M. & Woods, B. (2010). Cognitive Stimulation Therapy (CST): Effects on different areas of cognitive function for people with dementia. *International Journal of Geriatric Psychiatry, 25*(12), 1253–1258.

Spector, A., Thorgrimsen, L., Woods, B., Royan, L., Davies, S., Butterworth, M. et al. (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: A randomised controlled trial. *British Journal of Psychiatry, 183*, 248–254.

Subramaniam, P. & Woods, B. (2012). The impact of individual reminiscence therapy for people with dementia: Systematic review. *Expert Review of Neurotherapeutics, 12*(5), 545–555.

Surr, C. (2006). Preservation of self in people with dementia living in residential care: A socio-biographical approach. *Social Science and Medicine, 62*(7), 1720–1730.

Thompson, A. (2006). Qualitative evaluation of an Alzheimer Café as an ongoing supportive group intervention. In B.M.L. Miesen & G.M.M. Jones (Eds.), *Care-giving in dementia: Research and applications: Volume 4* (pp.291–312). London: Routledge.

Thompson, R. (2011). Using life story work to enhance care. *Nursing Older People, 23*(8), 16–21.

Urbas, S. (2009). Art therapy: Getting in touch with inner self and outside world. In E. Moniz-Cook & J. Manthorpe (Eds.), *Early psychosocial interventions in dementia: Evidence-based practice* (pp.146–155). London: Jessica Kingsley Publishers.

van Paasschen, J., Clare, L., Yuen, K., Woods, R.T, Evans, S., Parkinson, C. et al. (2013). Cognitive rehabilitation changes memory-related brain activity in people with Alzheimer's disease. *Neurorehabilitation and Neural Repair, 27*, 448–459.

Vernooij-Dassen, M., Draskovi,C.I., McCleery, J. & Downs, M. (2011). Cognitive reframing for carers of people with dementia. *Cochrane Database of Systematic Reviews* 2011, Issue 11. Art. No. CD005318.

Vink, A.C., Bruinsma, M.S. & Scholten, R.J.P.M. (2004). Music therapy for people with dementia. *Cochrane Database of Systematic Reviews* 2004, Issue 3. Art. No. CD003477.

Watts, S., Cheston, R. & Moniz-Cook, E. (2013). *Post-diagnostic support for people living with dementia: An interim report prepared for the Faculty of Psychologists working with Older People and the Dementia Action Alliance.* Retrieved 23 September 2014 from: www.dementiaaction.org.uk/assets/0000/3825/Faculty_of_Psychologists.pdf

Webster, J. & Haight, B. (Eds.). (2002). *Critical advances in reminiscence work: From theory to application.* New York: Springer.

Williamson, T. (2012). *A stronger collective voice for people with dementia.* York: Joseph Rowntree Foundation.

Woods, R.T. (2003). Evidence-based practice in psychosocial intervention in early dementia: How can it be achieved? *Aging and Mental Health, 7*(1), 5–6.

Woods, B., Spector, A.E., Jones, C.A., Orrell, M. & Davies, S.P. (2005). Reminiscence therapy for dementia. *Cochrane Database of Systematic Reviews* 2005, Issue 2. Art. No. CD001120.

Yale, R. (1995). *Developing support groups for individuals with early stage Alzheimer's disease.* York: The Maple Press Company.

Young, L., Howard, J. & Keetch, K. (2013). Once you start writing you remember more. *Journal of Dementia Care, 21*(2), 20–23.

Yu. F., Rose, K., Burgener, S., Cunningham, C., Buettner, L., Beattie, E. et al. (2009). Cognitive training for early-stage Alzheimer's disease and dementia. *Journal of Gerontological Nursing, 35*(3), 23–29.

Appendix 1: Some terminology used in this guide

Cognitive
Cognitive can mean any of a number of mental processes. Cognitive includes: knowing; thinking; learning; memory.

Carer/Caregiver
Name which is sometimes given to anyone who is involved in giving care or support to someone else. Carers or caregivers can be paid or unpaid. They can be a member of your family or a friend.

Dementia
A set of symptoms associated with an ongoing decline in the brain. Symptoms include memory loss, mental confusion and loss of emotional control. It is progressive, meaning symptoms worsen over time.

Intervention
Any action taken, medical or therapeutic, that has the purpose of lessening the effects of a disease or improving health.

Psychosocial
Relating to the interaction between one's mental state and social environment.

Psychology/Psychological
Relating to the human mind, specifically human thoughts, feelings and behaviour.

Quality of Life
General well-being in regards to health and happiness.

Reminisce/Reminiscence
Remembering and/or talking about previous life events and experiences.

Signpost/Signposting
Being given information on a condition, treatment or other services that can offer you support. It can also mean to be referred to other services.

Therapy/Therapist
Treatment of an illness, or the person administering that treatment.

Well-being
General health, happiness and contentment.

Appendix 2: Who are the professionals? What do they do?

Occupational Therapist

Works with people to help them overcome the effects of a disability caused by physical or psychological illness, ageing or accident. They help people to live as independently as possible, for example, in daily living activities.

Psychiatrist/Consultant Psychiatrist

A doctor who specialises in mental health. They are able to diagnose, treat, and prescribe medication for mental illnesses.

Psychologist/Clinical Psychologist

Someone who studies the mind and behaviour. A clinical psychologist works with people with mental or physical health problems, helping to assess, diagnose and treat them (but does not prescribe medication.).

Psychotherapist

A mental health professional who has had further specialist training in psychotherapy. A psychotherapist works with people who have a psychological illness, emotional and relationship difficulties, or problems such as stress. Psychotherapy can happen on an individual, marital, family or group basis.

Neurologist

A physician who specialises in disorders, injuries and diseases of the brain and the central nervous system. A neurologist can diagnose and, if possible, treat these disorders.

Therapist/CBT Practitioner

Someone trained in the use of psychological methods for helping clients overcome psychological problems. A CBT practitioner is a therapist who has had special training in conducting cognitive behavioural therapy.

Counsellor

Someone who has had training in counselling. They can help with personal, social, or psychological problems, giving the client someone to talk to on a one-to-one basis about their problems.

Support Worker

They provide emotional and practical support to individuals and their families who struggle to live independently because of mental or physical health problems, a learning disability, or emotional and relationship difficulties.

GP/General Practitioner

A doctor who you are registered with at your local practice. They treat general illnesses, and do not normally have a speciality.

Nurse

Someone trained in caring for people with a physical or mental health illness, in hospitals and in the community.

Psychiatric Nurse/Community Psychiatric Nurse

A nurse who specialises in mental health to help care for people with a mental illness.

Radiologist

A physician who specialises in radiology. Radiology involves the use of radiation for the diagnosis and treatment of disease.

Outreach worker

Someone who works in social services, the government or in the community. They provide services to help people and their families get the support they need and improve their quality of life.

Physiotherapist

Someone who is trained to help and treat people with physical problems caused by illness, accident or ageing. They work in hospitals and in the community.

Notes

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