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A guide to psychosocial interventions in early stages of dementia

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GUIDANCE



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Introduction

BACKGROUND TO THE 2ND EDITION

This is the second edition of the *Guide to Psychosocial Interventions in the early stages of Dementia*. The first edition was published in 2014, following consultations with people living with dementia in Kent, Birmingham, Glasgow, and Belfast, who attended groups affiliated to the Dementia Engagement and Empowerment Project (DEEP). We wanted to know what people thought about the uses of Psychology in the dementia care pathway, including psychological interventions after a dementia diagnosis. This work can be found in the following documents:

Clinical Psychology in the Early Stage Dementia Care Pathway: https://www.bps.org.uk/sites/www.bps.org.uk/files/Member%20Networks/Divisions/DCP/clinical_psychology_in_early_stage_dementia_care_pathway.pdf

A Guide to Psychosocial Interventions in Early Stages of Dementia, 1st Edition:

https://www.dementiavoices.org.uk/wp-content/uploads/2021/02/a_guide_to_psychosocial_interventions_in_dementia.pdf

In the course of these meetings, people living with dementia were often surprised to learn just how many approaches and interventions there are that can be helpful when trying to live as well as possible with dementia. People told us that they would like a catalogue, where they could look up, compare, and choose interventions, and we subsequently compiled the first guide. From feedback since its publication, we have learned that it has been useful not only for people with a dementia diagnosis, their families and friends, but also for professionals, dementia advisors, commissioners of services and policy makers.

In recent years there has been rapid development of interventions and of research into the effectiveness of psychological and psychosocial interventions in dementia. While the first edition contained 24 separate entries, the current edition therefore includes 36 entries to reflect this growth. For example, arts-based and creative interventions have been researched increasingly, and we have therefore created separate entries.

HOW THIS GUIDE WAS PUT TOGETHER

As in the previous edition, advice was followed from people living with dementia regarding the use of language, and an inclusive and accessible style. For example, we talk about 'family and friends' rather than using the term 'carers'. Wherever possible we are avoiding jargon, acronyms, and wording used in research or healthcare rather than in daily life.

While much care has been taken to reference the most relevant, recent and robust studies and provide summaries of evidence for each of the interventions, we have limited this to three references per entry and moved their full titles to the reference section at the end of the guide. Similarly, the full references for documents and the organisations recommending interventions are also listed in the reference section, which we hope improves readability of the entries.

Our criteria for including interventions in the first guide were widely consulted on and have not changed for this edition. As this has been developed for people living with dementia in the United Kingdom, we have only included interventions that are available at least somewhere in the UK. We are also taking care to focus on the interventions and on the evidence, and to avoid promoting specific providers.

This guide is aimed at people living through the earlier stages of dementia, and we have therefore not included interventions that are predominantly used in care homes or in later stages of dementia.

We have only included interventions that have at least some research evidence suggesting effectiveness for living well with dementia, for example improving memory and/or thinking skills, reducing anxiety, stress or depression, or increasing wellbeing, communication or social inclusion. We used a 'hierarchy of evidence' to help us decide which interventions and evidence to include. Evidence from gold standard randomised controlled trials (RCTs) and systematic reviews were preferred over peer-reviewed research studies and other published studies. Where an intervention is widely used or valued by people living with dementia but lacks this type of evidence, we have used smaller scale evaluation studies and case study reports.

As a psychology-based publication this guide does not include interventions that were deemed to have no or very little psychosocial component, or no psychological research into the effectiveness of the intervention.

CONTRIBUTORS

Where entries have been substantially reviewed or written by contributors other than the editorial team, this is also marked on the entry in the guide. We are immensely grateful to all who have contributed to reviews or written entries for this new edition, and we are proud of the diverse range of people who have given time to this project, including people living with dementia, clinicians, health professionals and some of our foremost researchers.

HOW TO USE THIS GUIDE

You may want to look through the guide from cover to cover, browsing through the alphabetically listed interventions. Alternatively, you could go to the second index (p.7), where we have grouped interventions together that may be useful for a particular need. For example you may want to look for therapies to assist with stress and anxiety, or you may want to look for interventions that improve memory and thinking skills.

Each entry gives a brief description of the intervention, its benefits and possible limitations, and gives information on where you can find out more, or where you might be able to access it. There are also references for research into their effectiveness, and which national body or organisation recommends the intervention.

It should be acknowledged that some interventions are much more easily accessible than others, and some areas have many more choices available than others. However, knowing that an intervention is available in other places in the UK may also help towards developing these more locally. It is hoped that this knowledge will empower people living with dementia and their families to ask for interventions that would be helpful to them, and to campaign for better availability where they are not yet offered. It is hoped that commissioners, planners and funders will also find this guide helpful as an overview of evidence-based psychosocial interventions that should be much more freely available to people with a new diagnosis of a dementia.

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, e.g. if feeling worried, anxious, 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 listed in alphabetical order from page 10 to 90.

REMOTE INTERVENTIONS AND THE IMPACT OF THE COVID-19 PANDEMIC

The Covid-19 pandemic has had a big impact on how we access services and our usual supports. Much of the support moved online, had to be delivered via telephone, or has been adjusted to meet new social distancing and infection control measures.

Similarly, many psychosocial interventions have had to adjust, whilst some have been put on hold entirely.

Where services have been available this may sometimes prompt a difficult decision around weighing up preferences and potential risk of attending in person versus participating remotely. More detail about particular risks for people with a diagnosis of dementia can be found on the websites of all major dementia organisations.

Many services have found creative and innovative ways to bring people together during the pandemic. In some cases, this has made services more accessible and brought together people in ways that may not have felt so possible in the past (for example joining a group with people in another country entirely).

Remote (video or telephone) interventions are not for everybody, but can offer unique opportunities, especially in times when seeing one another is not so possible, or for people who live in remote locations.

Many of the interventions mentioned in this guide have been offered remotely. As this provision is rapidly changing, we have not spoken about this further for each of the interventions, but we would encourage you, if interested, to explore the websites suggested to see what is available.

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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 would come into effect if you were to 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 to 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 may seem to others. Advance care planning may include:

- an Advance Decision to refuse treatment, for example resuscitation, or treatments which use blood products or intravenous antibiotics;
- 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 who you have chosen to speak for you if you lose mental capacity.

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 accordance with your wishes 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 an LPA.

WHO CAN SUPPORT ME WITH ADVANCE CARE PLANNING?

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

- wishes and preferences – family, friends, GP, carers etc.
- healthcare decisions – relevant professional
- advance decisions – doctor and solicitor.
- Lasting Power of Attorney – solicitor, Alzheimer's Society, and other helplines
- 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?

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>

The Alzheimer's Society has factsheets on Advance decisions and advance statements:

<https://www.alzheimers.org.uk/get-support/publications-factsheets>

WHO APPROVES/RECOMMENDS ADVANCE CARE PLANNING?

National Institute of Health and Care Excellence (NICE) Guidelines NG97, Standards 1.1.12 and 1.1.13 (National Institute of Health and Care Excellence, 2018).

Memory Services National Accreditation Programme (MSNAP) Standards, Standard 151, 154 (Royal College of Psychiatrists, 2020).

European Association for Palliative Care (Rietjens et al., 2017; van der Steen et al., 2014).

British Psychological Society (2014). *Clinical psychology in the early-stage dementia care pathway*.

Assistive technology: Advice and support

WHAT IS ADVICE AND SUPPORT ABOUT ASSISTIVE TECHNOLOGY?

'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 ADVICE AND SUPPORT ABOUT ASSISTIVE TECHNOLOGY 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 ADVICE AND SUPPORT AROUND ASSISTIVE TECHNOLOGY 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 are equipment and devices which can help you in the following areas:

- speaking, e.g. communication aides
- doing things independently at home
- keeping safe when going out, e.g. satellite navigation to help you find places, or GPS trackers to help others to find you
- memory, e.g. a medication monitor or alarm which will remind 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, 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 e.g. against falls, or by helping to regulate the temperature

There are many devices available. Any combination of devices can be used depending on your 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. 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?

Although you may be entitled to some financial assistance, assistive technology can 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 (such as those who work for social services) can talk to you about assistive technology and how you and your family can use it effectively. They can also advise you on whether you would be eligible for 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 is 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?

The Alzheimer's Society has factsheets on assistive technology:

<https://www.alzheimers.org.uk/get-support/publications-factsheets>

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.

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme* (MSNAP) Standards, Standard 188).

British Psychological Society (2014). *Clinical Psychology in the Early-Stage Dementia Care Pathway*.

Cognitive behavioural therapy (CBT)

WHAT IS CBT?

CBT is a term used to describe a number of ‘talking therapies’ which are used to overcome emotional and psychological problems. CBT is commonly used to treat stress, anxiety, and depression.

The word ‘cognitive’ refers to thinking, reasoning and memory.

There are similar therapies and developments of CBT, including acceptance and commitment therapy, cognitive analytic therapy, and mindfulness-based cognitive behavioural therapy.

WHO IS CBT FOR?

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

WHAT DOES CBT DO? HOW DOES IT WORK?

CBT aims to give you new skills to overcome current life challenges. It aims to change ways we think and the things we do that might be unhelpful. This may make it easier to deal with demanding situations or difficult emotions.

CBT 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 CBT TAKE?

The number of therapy sessions you are offered will depend on your needs and what your local service can offer. The number of sessions you have will be cooperatively decided by you and your therapist.

WHAT BENEFITS MIGHT I SEE FROM HAVING CBT?

CBT 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 CBT?

CBT 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. Not all CBT therapists are trained in working with people with dementia.

WHO CAN PROVIDE CBT?

CBT can be accessed in a number of ways, from self-help material, computerised programmes, working with a trained therapist or accessing a group.

This is available through NHS services, or private therapy services which you will have to pay for.

WHERE CAN I GO TO ASK FOR CBT?

A referral for CBT can be made by your GP or through your memory service if you are feeling stressed, anxious, worried, or depressed. You can also refer yourself for CBT through your local primary care therapy service.

WHERE CAN I FIND MORE INFORMATION ON CBT?

Information on CBT 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>

The Alzheimer's Society has factsheets on CBT:

<https://www.alzheimers.org.uk/get-support/publications-factsheets>

British Association for Behavioural & Cognitive Psychotherapies (BABCP). You can find a registered therapist from this website:

<http://www.babcp.com>

WHAT IS THE EVIDENCE FOR CBT?

There is evidence that psychological therapies including cognitive behaviour therapy reduce depression and anxiety and can be helpful to people living with dementia and the people close to them (Cheng et al., 2019; Cheston & Ivanecka, 2017; Orgeta et al., 2014).

WHO APPROVES/RECOMMENDS CBT?

Cognitive behaviour therapy is recommended by the British Psychological Society, the National Institute of Health and Care Excellence and the Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE) Guidelines NG97, Standard 1.7.11 (National Institute of Health and Care Excellence, 2018).

Memory Services National Accreditation Programme (MSNAP) Standards, Standard 178, 187 (Royal College of Psychiatrists, 2020).

British Psychological Society (2014). *Clinical psychology in the early-stage dementia care pathway*.

Cognitive rehabilitation (CR)

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 family members, friends and/or 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 practitioner, leading to agreement about which goals to work on together. The practitioner 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 tablet, 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 improve aspects of your daily life, such as keeping track of planned events and appointments, knowing names of people important to you, and keeping in touch with them, or managing household chores.

WHAT ARE THE POSSIBLE LIMITATIONS OF COGNITIVE REHABILITATION?

Cognitive rehabilitation will require effort from you, both during and outside of sessions. You will be asked to identify areas where you would like to see improvements. 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 a trained practitioner with a background in dementia care, nursing, occupational therapy, or clinical psychology.

WHERE CAN I ASK FOR COGNITIVE REHABILITATION?

A number of NHS, social care and private sector services across the country are now starting to offer cognitive rehabilitation.

In most areas, 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.

WHERE CAN I FIND MORE INFORMATION ON COGNITIVE REHABILITATION?

Information can be found through your memory service, your GP, or your dementia advisor. You can also download a 'My Life, My Goals' self-help guide at:

<https://www.alzheimers.org.uk/blog/life-after-dementia-diagnosis-guide-setting-reaching-goals>

WHAT IS THE EVIDENCE FOR COGNITIVE REHABILITATION?

Current evidence on the effectiveness of cognitive rehabilitation is promising, showing that cognitive rehabilitation is helpful in enabling people to attain individual goals relevant to managing everyday life (Bahar-Fuchs et al., 2013; Clare, Evans, Parkinson, Woods & Linden, 2011; Clare et al., 2019; Clare et al., 2010; Oltra-Cucarella et al., 2018; van Paaschen et al., 2013).

WHO APPROVES/RECOMMENDS COGNITIVE REHABILITATION?

Cognitive rehabilitation is recommended by the Royal College of Psychiatrists and the National Institute of Health and Care Excellence.

National Institute of Health and Care Excellence (NICE) Guidelines NG97, Standard 1.4.4 (National Institute for Health and Care Excellence, 2018).

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme (MSNAP) Standards*, Standard 185.

British Psychological Society (2014). *Clinical psychology in the early-stage dementia care pathway*.

Section contributed by Prof Linda Clare, Professor of Clinical Psychology of Ageing and Dementia, University of Exeter.

Cognitive stimulation therapy (CST) and maintenance cognitive stimulation therapy (MCST)

WHAT IS COGNITIVE STIMULATION THERAPY?

Cognitive stimulation therapy or 'CST' is a group therapy that is used to help strengthen a person's communications skills, thinking and memory. Maintenance Cognitive Stimulation Therapy groups aim to maintain the benefits that Cognitive Stimulation Therapy groups provide. Individual Cognitive Stimulation Therapy, which you can do with one other person is also available in a manualised form.

WHO IS COGNITIVE STIMULATION THERAPY FOR?

CST is for anyone who has a diagnosis of dementia, in mild to moderate stages.

WHAT DOES COGNITIVE STIMULATION THERAPY DO? HOW DOES IT WORK?

You would take part in structured group activities which stimulate different cognitive domains such as memory or language, which includes a strong social element. A typical CST session lasts for one hour and may involve news discussion, music, and a task such as categorising objects, word games, number games or comparison of faces and scenes.

Maintenance CST, like cognitive stimulation therapy, aims to help slow down cognitive decline. It follows on from a course of CST and is used to maintain its benefits. The sessions are the same as in CST, but often run for much longer.

Practitioners will work from a standardised manual on cognitive stimulation therapy which means most programmes will be similar but not exactly the same. A manual is now also available to use for individual cognitive stimulation therapy.

HOW LONG DOES COGNITIVE STIMULATION THERAPY TAKE?

Cognitive stimulation therapy usually runs for 14 sessions and you usually attend one or two sessions per week. Maintenance cognitive stimulation therapy (MCST) follows a 24-session manual but can be offered on a longer-term basis.

WHAT BENEFITS MIGHT I SEE FROM HAVING COGNITIVE STIMULATION THERAPY?

There are several benefits consistently demonstrated by global research. These benefits include:

- improving your cognitive functioning, including memory and language skills
- improving your confidence, and the way you feel about yourself 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 mood and quality of life

WHAT ARE THE POSSIBLE LIMITATIONS OF COGNITIVE STIMULATION THERAPY?

Cognitive stimulation therapy is usually offered in groups and follows a set programme. While adapted to the needs of people taking part, it may not suit everyone's taste.

WHO CAN PROVIDE ME WITH COGNITIVE STIMULATION THERAPY?

Practitioners trained in cognitive stimulation therapy, often occupational therapists, psychologists, mental health nurses, care workers and support workers. Often CST is available through your memory services or local mental health services, or the voluntary sector.

WHERE CAN I ASK FOR COGNITIVE STIMULATION THERAPY?

Your local memory service or dementia advisor will advise when and where CST is available.

WHERE CAN I FIND MORE INFORMATION ON COGNITIVE STIMULATION THERAPY?

Information on Cognitive Stimulation Therapy can be found on the internet:

www.cstdementia.com

<http://www.ucl.ac.uk/international-cognitive-stimulation-therapy>

You can also find information on cognitive stimulation therapy 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 cognition, including memory and language skills and quality of life. There is also increasing evidence that CST can reduce anxiety and depression. An interview study suggests improvements in mood, confidence and concentration, and highlights the supportive nature of the group. One study found that longer term Maintenance CST led to continuous benefits in these areas (Aguirre et al., 2014; Lobbia et al., 2018; Orrell et al., 2017).

WHO APPROVES/RECOMMENDS COGNITIVE STIMULATION THERAPY?

National Institute of Health and Care Excellence (NICE) Guidelines NG97, Standard 1.4.2 (National Institute of Health and Care Excellence, 2018).

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme* (MSNAP) Standards, Standards 182–184.

British Psychological Society (2014). *Clinical psychology in the early-stage dementia care pathway*.

Section contributed by Prof Aimee Spector, Professor of Old Age Clinical Psychology, University College London.

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](#). It is widely available on the internet, gaming consoles and smartphone applications ('apps') 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 (thus 'training' the brain). 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 continuously, 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 lists 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.
- Any benefits are likely to be restricted to the area being trained in and would not be more widely transferable.
- In order to have any noticeable effects, cognitive training needs to be personally tailored to your specific needs.

WHO CAN PROVIDE YOU WITH COGNITIVE TRAINING?

The exercises and games are usually self-administered, using the internet, books and technology (such as smartphone apps). Memory service programmes might be available in some areas.

WHERE CAN I GET COGNITIVE TRAINING (OR WHERE CAN I GET ADVICE ON COGNITIVE TRAINING)?

Specialist professionals with knowledge of dementia can give you advice on cognitive training. You can do general 'brain training exercises' by accessing intellectually stimulating materials, 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, these are likely to have limited effectiveness in terms of achieving your goals. It is best to ask a specialist professional for advice on maintaining your skills.

WHAT IS THE EVIDENCE FOR COGNITIVE TRAINING?

Evidence suggests that people get better at the tasks that they practice, but there is no improvement in other areas. Interventions that are more structured and focused are more effective overall (Bahar-Fuchs et al., 2013; Kallio et al., 2017; Yu et al., 2009).

WHO APPROVES/RECOMMENDS COGNITIVE TRAINING?

At the time of writing, NICE Guidelines for dementia support *do not* recommend cognitive training for people with mild to moderate Alzheimer's disease – standard 1.4.7 (National Institute for Health and Care Excellence, 2018).

Compassion focused therapy

WHAT IS COMPASSION FOCUSED THERAPY?

Compassion focused therapy is a type of talking therapy used to treat a range of psychological difficulties. It can help overcome anxiety, depression, and the emotional consequences of stressful life events.

The term ‘compassion’ refers to an awareness of suffering with an intention to alleviate or reduce it.

WHO IS COMPASSION FOCUSED THERAPY FOR?

Compassion focused therapy was developed to help people who are experiencing self-criticism, embarrassment, or feelings of shame, regardless of any diagnoses they may have been given (e.g. depression, anxiety, dementia). You may want to try compassion focused therapy if you are finding it difficult to come to terms with a diagnosis of dementia.

WHAT DOES COMPASSION FOCUSED THERAPY DO/INVOLVE? HOW DOES IT WORK?

Compassion focused therapy aims to help you cope with the emotional consequences of life events. It helps you understand how our ‘tricky brains’ work. Learning about this can help you to settle your body and manage any self-critical thinking, freeing you up to act differently. It can also encourage you to be more compassionate to yourself, while allowing you to better accept compassion from others.

The therapy usually involves meeting a compassion focused therapist, who will listen to your experiences and concerns with compassion and will help you (and someone close to you if you would like them to come along too) learn about how you relate to yourself and others, and how compassion can help you cope with difficult emotions.

HOW LONG DOES COMPASSION FOCUSED THERAPY TAKE?

This will depend on your current need. Session numbers are usually agreed upon with your therapist and often lead to a course of several meetings.

WHAT BENEFITS MIGHT I SEE FROM HAVING COMPASSION FOCUSED THERAPY?

Compassion focused therapy aims to develop a shared understanding of our ‘tricky brains’ and how they can lead us to experience strong emotions in relation to life difficulties. It will help you explore how you are coping and as a result you may:

- develop new ways to encourage and support yourself in times of need
- feel more able to allow others to help you
- focus on your strengths and how you can carry on leading an active life

WHAT ARE THE POSSIBLE LIMITATIONS TO COMPASSION FOCUSED THERAPY?

Compassion focused therapy is a relatively new treatment, meaning it continues to be developed through research. Given its focus on how you can be less critical and more supportive of yourself it may not be for everyone and there are, of course, alternative talking therapies that may suit you instead (see the [What is my need?](#) section for more information).

WHO CAN PROVIDE ME WITH COMPASSION FOCUSED THERAPY?

A therapist trained in compassion focused therapy can provide you with this therapy. This may be available via your local NHS services or through the private sector.

WHERE CAN I ASK FOR COMPASSION FOCUSED THERAPY?

Your GP can refer you for a talking therapy and could specify Compassion Focused Therapy, if it is available, either via your local Memory Service or your local mental health services.

WHERE CAN I FIND MORE INFORMATION ABOUT COMPASSION FOCUSED THERAPY?

Information on compassion focused therapy can be found via The Compassionate Mind Foundation <https://www.compassionatemind.co.uk/>

The Compassionate Mind Foundation's International directory of CFT-interested therapists can also help you find a therapist <http://cfttherapist.com/>

WHAT IS THE EVIDENCE FOR COMPASSION FOCUSED THERAPY?

There is evidence that compassion focused therapy can help people living with early-stage dementia, as well as family members (Craig, Hiskey & Spector, 2020; Collins et al., 2018; Craig, Hiskey, Royan, Poz & Spector, 2018).

WHO APPROVES/RECOMMENDS COMPASSION FOCUSED THERAPY?

National Institute of Health and Care Excellence (NICE) Guidelines NG97, Standard 1.7.11 (National Institute of Health and Care Excellence, 2018).

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme (MSNAP) Standards*, Standard 187.

British Psychological Society (2014). *Clinical psychology in the early-stage dementia care pathway*.

Section contributed by Dr Catriona Craig, Clinical Psychologist, Oxford Health NHS Foundation Trust & Dr Syd Hiskey, Consultant Psychologist, Oaks Hospital, Essex.

Counselling and psychotherapy

WHAT IS COUNSELLING? WHAT IS PSYCHOTHERAPY?

Counselling and psychotherapy are forms of ‘talking therapy’ for personal issues, such as stress, worry, anxiety or depression. Counselling may be briefer and provides a listening space, while psychotherapy may be longer and look more closely at emotional or behavioural difficulties. They involve sharing your problems with your therapist or counsellor in a confidential setting.

There may also be opportunities to talk together as a couple or with a member of your family or a friend. 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 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 your difficulties.

HOW LONG DOES COUNSELLING OR PSYCHOTHERAPY TAKE?

How long you are seen for tends to be a joint decision between you and your therapist or counsellor. 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. Many services have a maximum number of sessions they can offer. 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. 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.

WHERE CAN I FIND MORE INFORMATION ABOUT COUNSELLING AND PSYCHOTHERAPY FOR MYSELF?

You can find out more about counselling and psychotherapy from the following websites:

<http://www.alzheimers.org.uk/>

<http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/types-of-therapy.aspx>

You can 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 (Cheston & Ivanecka, 2017; Junaid & Hedge, 2007; Lipinska, 2009).

WHO APPROVES/RECOMMENDS COUNSELLING AND PSYCHOTHERAPY?

Counselling and psychotherapy are recommended by NICE, the British Psychological Society and the Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE) Guidelines NG97, Standard 1.7.11 (National Institute for Health and Care Excellence, 2018)

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme (MSNAP) Standards*, Standards 187 & 190.

British Psychological Society (2014). *Clinical psychology in the early-stage dementia care pathway*.

Section contributed by Prof Rik Cheston, Professor of Dementia Research, University of the West of England.

Creative arts therapies

WHAT ARE CREATIVE ARTS THERAPIES?

Creative arts therapies are a type of psychotherapy which use media such as painting, literature, poetry, 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](#), [dramatherapy](#), or [dance and movement therapy](#) 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 may be able to help with emotional difficulties, motivation, meaning in life 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 you want an alternative to talking therapies.

WHAT DO CREATIVE ARTS THERAPIES DO? HOW DO CREATIVE ARTS THERAPIES WORK?

The creative art therapies can take place individually or in groups, and usually involves the creation and/or discussion of one of the arts in a confidential, therapeutic environment such as a clinic, hospital or in private practice. 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 and interpret their meaning.

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
- help with anxiety and worry
- improving wellbeing 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 arts therapy, such as music therapy, (visual) art therapy and dramatherapy, among others. While sessions involving participatory arts can be offered by many different types of professionals as interesting activities, the creative arts therapies address 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 multidisciplinary teams in hospitals, daycentres, hospices, care homes, therapy centres and in private practice across the UK. Your GP, your local Alzheimer's Society or Age UK office may be able to recommend an arts therapist near you.

WHERE CAN I FIND MORE INFORMATION ABOUT CREATIVE ARTS THERAPIES?

Your GP or other health care professional or memory service may be able to provide you with more information. You may also want to contact the following organisations for information about an arts therapist in your area:

British Association of Art Therapists (BAAT): <https://www.baat.org/>

WHAT IS THE EVIDENCE FOR CREATIVE ARTS THERAPIES?

There are many subjective accounts by people with dementia and family members, and several case-study research reports by clinical academics, relating to the benefits of having creative arts therapies, such as improved wellbeing. However, objective measures of benefits of this type of therapy are only beginning to be investigated fully (Beard, 2012; Urbas, 2009).

WHO APPROVES/RECOMMENDS CREATIVE ART THERAPIES?

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

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme (MSNAP) Standards*, Standard 191.

Section contributed by Prof Paul Camic, Honorary Professor of Health Psychology, Dementia Research Centre, University College London.

Creative writing

WHAT IS CREATIVE WRITING?

Creative writing covers a huge array of writing styles, from poetry, prose, fiction to screen and stage writing, including memoirs and personal reflective pieces. Creative writing sessions are not competitive, and there is no need for any previous experience. Creative writing groups are often most enjoyed by people who have never tried it before.

WHAT DOES CREATIVE WRITING INVOLVE? HOW DOES IT WORK?

Creative writing generally happens within a group and is led by a tutor or facilitator. Although writing may be seen as a solitary activity, there is in fact a tremendous social side to writing groups. As people begin to share their perspectives and memories, connections are forged, the understanding of each other deepens and friendships are built.

In a creative writing session, you will explore themes and ideas using your own experience as well as your imagination to create short pieces of writing. Creative prompts are provided by the tutor, ensuring everyone in the group is able to create something they are pleased with.

WHO IS CREATIVE WRITING FOR?

Your group facilitator's job is to ensure everything is accessible, enjoyable, and well-paced for everyone. Many people who join creative writing groups have not written anything since they left school. If writing is a challenge, it is usually possible to have a friendly volunteer scribe for you.

HOW LONG DOES CREATIVE WRITING TAKE?

Creative writing sessions usually last between one and two hours, although occasionally you may find a creative writing retreat day. Courses of sessions may last a few weeks or a full term. Within sessions, each writing activity will take between five and fifteen minutes. Writers are then invited to reflect on what they have written, sometimes sharing their work (but no one is ever forced to!).

WHAT BENEFITS MIGHT I SEE FROM CREATIVE WRITING?

Participants have reported improved clarity of thought, improvements in their speaking and a great confidence boost. There is a deep sense of satisfaction through crafting a poem that causes your friend to say, *Yes! I know just what you mean!* The social benefits are tremendous, giving opportunities to make friends and share experiences.

There is also purpose to be found in each task. This ripples out into daily life, so that writing often becomes an enjoyable part of daily routines: after all, all you need is paper and a pen, and suddenly the whole world is at your fingertips.

WHAT ARE THE LIMITATIONS OF CREATIVE WRITING?

Although creative writing is therapeutic, it is not strictly speaking 'therapy'. Group facilitators will not be clinically trained. Unless you can physically join a group, you need to be able to access groups online. Research evidence on the mental health benefits is currently still limited.

WHO CAN OFFER ME CREATIVE WRITING?

Courses are generally offered by individuals. Often these facilitators are writers themselves, working on a freelance basis and connecting into larger organisations.

Joining a local DEEP group or Service User Involvement Group will ensure people running events locally to you will visit to share news of groups with you.

WHERE CAN I ASK FOR CREATIVE WRITING?

Creative writing groups pop up all over the place: libraries can be a good starting point. The listing on the Arts4Dementia website are also useful. Local dementia-focused organisations may carry listings or run groups. Age UK centres may carry information if they are running courses. Your local DEEP or Service User Involvement Group are probably the best place to start.

WHERE CAN I FIND OUT MORE INFORMATION ABOUT CREATIVE WRITING FOR MYSELF?

Your healthcare professional or memory service clinic may be able to provide you with local information.

Further information can be found here at the Arts4Dementia website (<https://arts4dementia.org.uk>) or by searching for 'creative writing' on the Alzheimer's Society website (<https://www.alzheimers.org.uk/>).

The five-session Time and Place poetry course for people living with dementia can be accessed online for free at <https://www.lizjenningswriter.com/2020/05/26/time-and-place-poetry-group-welcome-and-session-1/>. Poems can be posted online there if you wish to share your work.

Welcome to Our World – A Collection of Life Writings by People Living with Dementia (Jennings, 2014) is an example of creative writing by people living with dementia, with exercises and further information that can be found at the end of the book (ISBN-13 978-0-99307-420-2).

WHAT IS THE EVIDENCE OF CREATIVE WRITING?

There have been few higher-level studies into the benefits of creative writing for people living with dementia. However, there are some recent examples of groups coming together to write creatively, in the format of poems, short film scripts or life stories. Because the activity of creative writing can be so varied, and has been done in so many different settings, it is difficult to judge how effective it is at this stage. However, both participants and facilitators have spoken positively about the experience (Aadlandsvik, 2008; Gould, 2013; Various, 2021).

WHO APPROVES/RECOMMENDS CREATIVE WRITING?

The National Institute for Health and Care Excellence (NICE) recommends that a range of activities to promote wellbeing are offered, that are tailored to personal preference, in NG97, standard 1.4.1 (National Institute for Health and Care Excellence, 2018).

Section contributed by Liz Jennings, writer, speaker and group facilitator and Keith Oliver, Dementia Service User Envoy, Alzheimer's Society Ambassador.

Dance and movement therapy

WHAT IS DANCE AND MOVEMENT THERAPY?

This describes a group of therapies and activities involving any type of dancing that helps people to feel better. Dance therapy requires a professionally qualified therapist to lead it, whereas therapeutic dance does not. It most commonly takes place in a social setting with other people but can be undertaken between a couple at home, or even alone. This section focuses on dance and movement therapy in a social setting.

WHO IS IT FOR?

Dance and movement therapy is for everyone who enjoys moving to music. If you are directly affected by dementia, activities can simultaneously involve you, your family, and your wider social circle. You do not have to have previous dancing experience or any level of skill.

WHAT DOES IT INVOLVE?

There are two types of therapeutic dance opportunities:

- activities specifically for people affected by dementia; or
- open community dances or classes that have provision for people with different abilities.

In both cases, activities are likely to be held in a community hall or dance studio. They will be led by a dance practitioner who has suitable experience/knowledge. Sessions are commonly 1 to 1.5 hours long, often with refreshment and friendly conversation opportunities.

HOW DOES IT WORK?

Almost everyone can move to music, however slightly. Dance can simultaneously support people's physical and cognitive functioning (e.g. memory, judgement, reasoning) and mental and social wellbeing.

It improves wellbeing through the stimulation of blood flow, and of multiple parts of the brain, such as those involved in movement, coordination, thinking and organising, as well as the emotional centre.

HOW LONG DOES IT TAKE?

Therapeutic dance is a short or long-term activity. You may wish to enrol in a dementia-specific dance course, which tends to be a set number of sessions, or an open community dance class that could continue for many months or years. Your preference will guide you to the most suitable activities, for example an ongoing Line Dancing class or a six-week Belly Dancing course.

WHAT BENEFITS MIGHT I SEE?

The primary benefits from dance and movement therapy and dancing with others are improvements in physical movement and balance, lowering the risk of falls, better stamina, improved mood and a sense of social connectedness.

WHAT ARE THE POSSIBLE LIMITATIONS?

The joy of dance and movement therapy is that everyone can take part according to their current abilities, whether physically fit or in a wheelchair. There are, however, some considerations. You may find that the

content or pace of a particular class does not suit you. If you have been unwell, had an injury or an operation you will need to seek the advice of your doctor before enrolling/returning to a dance activity.

WHO CAN PROVIDE DANCE AND MOVEMENT THERAPY?

All community dance practitioners are used to working with people with different abilities, so if you come across a community dance class that appeals to you it may be worth trying it to judge for yourself its suitability. Alternatively, you could contact the dance practitioner before attending to ask what the class involves and any other questions you may have.

For dementia-specific classes the dance practitioners will be specifically trained to work with people affected by dementia. Some dementia-specific dance courses have been funded by the NHS or charitable trusts. At present enrolling in open public classes is not usually funded.

WHERE CAN I ASK FOR DANCE AND MOVEMENT THERAPY?

Your dementia advisor or local memory services link worker will be able to guide you to information on dances/classes/courses in your area. For open community classes/dances, you can often find information in your local library, or search the internet.

WHERE CAN I FIND MORE INFORMATION ON DANCE AND MOVEMENT THERAPY?

You can search for 'dance for dementia' on the internet, or you can look at the websites:

www.alzheimers.org.uk

www.arts4dementia.org.uk

Both of these websites provide information on dance activities in your local area.

WHAT IS THE EVIDENCE FOR DANCE AND MOVEMENT THERAPY?

Research evidence on the benefits of dance for people affected by dementia include a report on the ongoing 'Remember to Dance' project (Vella-Burrows & Wilson, 2016):

artshealthresources.org.uk/docs/remember-to-dance-evaluating-the-impact-of-dance-activities-for-people-in-different-stages-of-dementia/.

Other studies are listed on the National Institute of Health and Care Excellence's website: evidence.nhs.uk/search?q=dance+dementia.

WHO APPROVES/RECOMMENDS DANCE AND MOVEMENT THERAPY?

Dance and movement therapy is recommended by the Royal College of Psychiatrists.

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme (MSNAP) Standards*, Standard 191.

Section contributed by Dr Trish Vella-Burrows, Principal Research Fellow, Sidney De Haan Research Centre for Arts and Health, Canterbury Christ Church University.

(Support from) dementia advisors

WHAT IS A DEMENTIA ADVISOR?

A dementia advisor is there to provide you with support throughout your journey – 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 wellbeing 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 you may require. (In some areas the dementia advisor role is called a ‘dementia navigator’).

The 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 Age UK.

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 find the Alzheimer's Society Factsheet about dementia advisors on the internet here:

<https://www.alzheimers.org.uk/get-support/publications-factsheets>

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.

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme (MSNAP) Standards*, Standard 162.

Department of Health, National Dementia Strategy (Department of Health, 2009). 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.

Dementia choirs

WHAT IS A DEMENTIA CHOIR?

Dementia choirs, sometimes called ‘singing for the brain groups’ are places that bring people with dementia and their friends and families together to sing a variety of new and old songs in a fun and friendly environment. Although [music therapy](#) and other [creative arts therapies](#) may also include elements of music and singing, a dementia choir focuses on singing together as a group.

WHO ARE DEMENTIA CHOIRS FOR?

Choirs are open to everyone no matter your previous experience of singing or as part of a choir. You do not need to be a ‘good singer’ to benefit. People are often able to recall a familiar song even when other areas of memory are not so strong, and sometimes singing can feel easier even when finding the right word can be difficult.

WHAT DOES A DEMENTIA CHOIR INVOLVE? HOW DOES IT WORK?

Choirs may involve vocal warmups, and a chance to sing old songs and learn new songs as part of a group. There are usually volunteers, staff or facilitators who are available to support you if needed.

HOW LONG DO DEMENTIA CHOIRS TAKE?

Dementia choirs are usually ongoing groups that meet regularly, for example once a week. Sessions can range in length but are usually around two hours and often include some time for socialising.

WHAT BENEFITS MIGHT I SEE FROM ATTENDING A DEMENTIA CHOIR?

- Songs can bring back old memories and feelings, connecting us with our past.
- Learning new skills and songs can be rewarding.
- Singing has been shown to improve our wellbeing.
- It has been shown to strengthen a range of cognitive skills.
- Singing with others in a choir can be hugely enjoyable.

WHAT ARE THE POSSIBLE LIMITATIONS OF DEMENTIA CHOIRS?

Singing, and singing in front of others, can feel like a daunting experience that not everyone is comfortable with. Singing and learning new songs may be challenging.

WHO CAN OFFER DEMENTIA CHOIRS?

Dementia choirs are often facilitated by voluntary or community organisations, such as the Alzheimer's Society or local groups.

WHERE CAN I FIND MORE INFORMATION ABOUT DEMENTIA CHOIRS FOR MYSELF?

You can ask for more information from your memory service, or local voluntary services such as Age UK or a [Dementia Café](#).

Alzheimer's Society also has information about 'Singing for the brain' groups:

<https://www.alzheimers.org.uk/get-support/your-support-services/singing-for-the-brain>

WHAT IS THE EVIDENCE FOR DEMENTIA CHOIRS?

Although many people who participate in choirs speak about their positive experiences there have been few higher-level pieces of research looking into the effectiveness of dementia choirs (Clark, Tamplin & Baker, 2018; Robertson-Gillam, 2008; Sheets et al., 2020).

WHO APPROVES/RECOMMENDS DEMENTIA CHOIRS?

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme (MSNAP) Standards*, Standard 191.

Dementia dogs

WHAT ARE DEMENTIA DOGS?

The Dementia Dog Project is a charity run project in partnership with Alzheimer Scotland. They provide two types of assistance dogs for people in the early stages of dementia and their families. The two types of dogs they provide are ‘Dementia Assistance Dogs’ and ‘Dementia Community Dogs’. ‘Dementia Assistance Dogs’ are trained to live at home with families, where a person has an early-stage diagnosis and lives with someone who cares for and supports them full-time.

‘Dementia Community Dogs’ involves dog-assisted therapy intervention visits from a Dementia Community Dog and their handler for 6–8 weeks, working alongside a healthcare professional to achieve a personal goal.

WHO ARE DEMENTIA DOGS FOR?

Dementia assistance dogs are for anyone with a diagnosis of early-stage dementia, who lives at home with a partner who could also be classed as their ‘full-time carer’. You should be able to care for a dog at home full-time, for example you should have a garden.

Dementia community dogs are for anyone with a diagnosis of early to moderate stage dementia who may not be able to have a dog at home full-time but could benefit from goal-focused therapy visits to help rebuild independence and confidence, and to help with physical, social, emotional, or cognitive functioning.

WHAT DOES A DEMENTIA DOG INVOLVE? HOW DOES IT WORK?

Dementia assistance dogs live with you at home full-time as your pet. Dementia assistance dogs’ skills are matched to the person and the support they require, to ensure a lasting happy partnership. Dementia assistance dogs can help with everyday tasks such as retrieving a medication pouch or placing a water bottle into a person’s lap in response to an alarm, to help remind them to take their medication or to hydrate. They are also trained to help maintain routines, for example by gently waking someone in the morning, or helping to remove items of clothing when it is time to get undressed for bed.

Dementia community dogs do not live with you, this is a shorter intervention with a community focus. Their handler would work closely with you and with a health or social care professional to deliver up to six structured, goal focused sessions, to achieve a goal set jointly by you and your healthcare professional. This could be a goal such as feeling confident enough to get the bus into town, or to attend a local coffee morning.

HOW LONG DO YOU HAVE A DEMENTIA DOG FOR?

If you have a dementia assistance dog, this is your dog for the rest of your life. For a dementia community dog, this is a short-term intervention, with up to six sessions over 6–8 weeks. These sessions can be spaced out to suit your needs (for example one session per week, or fortnight).

WHAT BENEFITS MIGHT I SEE FROM HAVING A DEMENTIA DOG?

Dementia dogs can help people with dementia and their families to feel more connected with each other and their communities. They can help you to build confidence and independence and be a great way for you to socialise with others when out and about. They can also be a source of emotional support, providing love and companionship to help with the daily challenges you may face.

WHAT ARE THE POSSIBLE LIMITATIONS TO HAVING A DEMENTIA DOG?

- You may be allergic to dogs.
- You are only eligible for a dementia assistance dog (who lives with you full-time) if you have a partner or carer, and a garden.
- The responsibility and timeframe of having a pet should be considered. It may be more feasible to be involved in the dementia community dog programme if you cannot provide for a dog full-time at home.

WHO CAN PROVIDE ME WITH A DEMENTIA DOG?

Dementia Dogs are a charity, and a relatively new approach. Currently Dementia Dogs are only available if you live in Scotland or Australia. It is planned that in future it will become available more widely in the UK.

WHERE CAN I ASK FOR A DEMENTIA DOG?

If you live in Scotland, you can be referred to the Dementia Dog Project by a healthcare professional, for example in your memory service or your GP. You can also self-refer through their website: www.dementiadog.org.

WHERE CAN I FIND MORE INFORMATION?

You can find out more information about Dementia Dogs through their website:

www.dementiadog.org

You can also email them at: bark@dementiadog.org

Or you can find out more about Dementia Dogs through Alzheimer Scotland: 0808 808 3000

WHAT IS THE EVIDENCE FOR DEMENTIA DOGS?

As this is a relatively new intervention, there is currently limited evidence published (Thompson-Bradley & Christie, 2020).

WHO APPROVES/RECOMMENDS DEMENTIA DOGS?

The National Institute for Health and Care Excellence (NICE) recommends that a range of activities to promote wellbeing are offered, that are tailored to personal preference, in NG97, standard 1.4.1 (National Institute for Health and Care Excellence, 2018).

Dementia/memory cafés

WHAT IS A DEMENTIA CAFÉ OR MEMORY CAFÉ?

Dementia cafés are informal meeting groups which are open to anyone affected by dementia to drop in when they like. They are a place 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.

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. Often, they take place once a week or once a fortnight. 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 with similar experiences in a friendly, relaxed, and social environment, 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. It is important to be aware that there will be people with a range of different experiences of dementia, including people who are at different stages, or whose dementia affects them in different ways. There is a possibility that you may find this upsetting.

WHO PROVIDES DEMENTIA CAFÉS OR MEMORY CAFÉS?

Groups are often organised by voluntary sector organisations such as Age UK and Alzheimer's Society, amongst others. They are often 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, through memory services, the Alzheimer's Society or the internet.

WHERE CAN I FIND MORE INFORMATION ABOUT DEMENTIA CAFÉS?

NHS Choices: <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/>

This link shows an overview of what a memory café is, as well as suggestions on how to get one started: <http://repod.org.uk/downloads/REPoD-mc-guide.pdf>

These organisations will have information at hand on local opportunities:

Age UK Advice service: 0800 055 6112 or www.ageuk.org.uk

Alzheimer's Society: (Support line) 0333 150 3456 or www.alzheimers.org.uk

Dementia Web: www.dementiaweb.org.uk

WHAT IS THE EVIDENCE FOR DEMENTIA CAFÉS?

Jones (2010) summarises how and why dementia cafés (here called an Alzheimer café) work. It includes anecdotes, interviews and comments on themes that are discussed at meetings.

An internal report by the Alzheimer's Society found that although cafés differed in the way they operated, they all contributed to helping people with dementia and family members to live well (Tooke & Radcliffe, 2014).

A study about family and/or carers' experiences identified the main themes as: peer support, developing social networks, reducing isolation, access to information and support, and respite from a caring role (Greenwood et al., 2017).

WHO APPROVES/RECOMMENDS DEMENTIA CAFÉS?

Dementia cafés are recommended by the National Institute for Health and Care Excellence and the Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE) Guidelines NG97, Standard 1.4.1 (National Institute of Health and Care Excellence, 2018).

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme (MSNAP) Standards*, Standard 140.

Dramatherapy

WHAT IS DRAMATHERAPY?

Dramatherapy is a form of psychological therapy in which all the performance arts are utilised within the therapeutic relationship. Dramatherapy addresses a wide range of personal emotional difficulties, including dementia, depression or mood changes, loss, and grief. Dramatherapy is also effective in promoting health as an early intervention. Drama therapists are both artists and clinicians who draw on their trainings in theatre/drama and therapy to bring about psychological, emotional, and social changes. The therapy gives equal validity to body and mind within the dramatic context; stories, myths, play texts, puppetry, masks, and improvisation are examples of the range of artistic interventions a drama therapist may employ. These enable the client to explore difficult and painful life experiences through an indirect approach.

WHO IS DRAMATHERAPY FOR?

A common myth is that you must be good at acting to engage in dramatherapy work. However, this is not the case. Dramatherapy is an intervention suitable for people with dementia at every stage. Drama therapists are trained to adapt and adopt different methods to work closely with people in diverse populations. They work qualitatively in a non-verbal way using a range of creative models, attuning to the emotions and needs of clients on an individual basis.

WHAT DOES DRAMATHERAPY INVOLVE? HOW DOES IT WORK?

Dramatherapy treatment invites the client to express their difficulties through a creative medium. This not only gives opportunity to find a voice for things that are too difficult to say, but it also gives a depth to the expression that words alone do not allow for. People with dementia despite impaired language ability are able to access rich memories creatively through story, music, mime, movement and touch.

HOW LONG DOES DRAMATHERAPY TREATMENT TAKE?

Sessions usually last between one and two hours. The number of sessions can be dependent on individual need and desire. Dramatherapy treatment can take place on an individual or group basis.

WHAT BENEFITS MIGHT I SEE FROM HAVING DRAMATHERAPY TREATMENT?

The benefits to service users can extend well beyond therapy sessions. Val Huet, (chief executive of the British Association of Art Therapists) says 'Arts therapists and drama therapists are skilled at engaging hard to reach service users of all ages, regardless of their conditions. Outcomes can include improved social and communication skills, as well as increased confidence and self-esteem, enabling them to play a more integrated role in society'. Participants often feel uplifted, more creative, and more spontaneous.

WHAT ARE THE LIMITATIONS OF DRAMATHERAPY?

Dramatherapy as an intervention has been around for 40 years but historically it has been difficult to obtain funding for it. Recently there has been more recognition of the benefits of using non-verbal methods with people with dementia.

WHO CAN OFFER DRAMATHERAPY?

Dramatherapy can only be provided by HCPC registered practitioners who have obtained their master's degree. Drama therapists are trained in both psychological and arts-based assessment and evaluation techniques. Drama therapist is a title protected by law and subject to robust rules, codes of ethics and HCPC guidelines. All drama therapists whether working privately or in a clinical setting are required to undertake training and regular supervision on their clinical work.

WHERE CAN I ASK FOR DRAMATHERAPY?

Drama therapists can be found working within multidisciplinary teams in hospitals, day centres, hospices, care homes, community mental health teams and in private practice. You usually need a referral to a specialist mental health or memory service from your GP to access Dramatherapy. The British Association of Dramatherapy (www.badth.org.uk) holds a register of drama therapists (who may also work privately).

WHAT IS THE EVIDENCE FOR DRAMATHERAPY?

The evidence base for dramatherapy is limited as most dramatherapy studies are qualitative rather than outcome based. These studies have reported that participants benefit from improved self-esteem, quality of life and social contact (Beard, 2011; Schmitt & Frölich, 2007).

WHO APPROVES/RECOMMENDS DRAMATHERAPY?

The British Medical Association (BMA) stated: 'Theatre and drama are the most integrative of all the arts: they include singing, dancing, painting, sculpture, storytelling, music, puppetry, poetry, and the art of acting. An evaluation of the role of therapeutic theatre for people lacking in communication, cognitive and social skills showed a positive effect in alleviating these disabilities. Dramatherapy responds to the deep psychological need of people with dementia to express and understand their own world' (BMA, 2011).

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

Royal College of Psychiatrists (2020). Memory Services National Accreditation Programme (MSNAP) Standards, Standard 191.

Section contributed by Kate Richardson, Drama Therapist, Kent & Medway NHS and Social Care Partnership Trust.

Family/systemic therapy

WHAT IS FAMILY THERAPY?

Family therapy and systemic therapy are forms of talking therapy. They aim to bring together couples, families, or all those in close relationship to talk about what is happening to them. A common focus is on helping people to review the ways that they communicate with each other in a non-blaming and a non-judgemental way. Family therapy typically assumes a shared responsibility towards overcoming difficulties.

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 together.

WHAT DOES FAMILY THERAPY INVOLVE? HOW DOES IT WORK?

You would usually choose who you might want to invite to attend a family therapy session with you. Family therapy aims to improve understanding between people and help them 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 a small number of sessions, depending on your needs. The frequency of meetings may differ, from once a week to once a month or more.

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 by learning new ways of dealing with difficult issues together. Family therapy aims to improve your wellbeing and the wellbeing 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 may be available in your local community mental health team, or via a memory clinic, or via dementia assessment and treatment service. It is a specialist service that is likely to need a referral from a psychiatrist or mental health professional, rather than a GP. It can also be accessed privately.

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 (Benbow & Sharman, 2014; Carr, 2014; Richardson, 2005).

WHO APPROVES/RECOMMENDS FAMILY THERAPY?

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

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme (MSNAP) Standards*, Standard 151, 154.

British Psychological Society (2014). *Clinical psychology in the early-stage dementia care pathway*.

Involvement groups for people with dementia

WHAT IS AN INVOLVEMENT GROUP?

Involvement groups have grown from the realisation that people with a diagnosis of dementia are essential in the development and improvement of dementia services in local communities as well as nationally. These groups meet to discuss how improvements can be made in services and in the community and to advise professionals, services, and policy makers. People who use services are sometimes called service users, and the groups are therefore sometimes called service user involvement groups. Groups are run and organised in a variety of ways, both locally and nationally, and in online networks.

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 to support the person with dementia. Some groups are co-ordinated by organisations such as NHS trusts or charities. Groups usually involve some social time as well as 'business' time.

HOW LONG CAN I ATTEND AN INVOLVEMENT GROUP?

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 challenge stigma and prejudice
- finding a new sense of self-worth and purpose
- developing new skills and improving confidence

WHAT ARE THE POSSIBLE LIMITATIONS OF INVOLVEMENT GROUPS?

Depending on where your group meets, you may need to arrange your own transport. Taking part in regular meetings and events may mean committing considerable time and energy. There might 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?

Groups can be organised and led by a professional but can also be run by group members themselves. Voluntary sector organisations, such as DEEP (Dementia Engagement and Empowerment Project), YoungDementia 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 in your memory service. The following websites may also have relevant information:

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

Alzheimer's Society: <https://www.alzheimers.org.uk/get-involved>

Three Nations Dementia Working Group: <https://www.3ndementiawg.org/>

YoungDementia Network: <https://www.youngdementiauk.org/young-dementia-network>

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 evidence about involving people with dementia in research and in-service provision in general (Cheston et al., 2000; Kenny et al., 2016; Litherland, 2015).

WHO APPROVES/RECOMMENDS INVOLVEMENT GROUPS?

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme, 7th edition*. Royal College of Psychiatrists: London. Standard numbers: 3 and 7.

Contributed by Chris Norris, Dementia Envoy, Alzheimer's Society Ambassador and Keith Oliver, Dementia Service User Envoy, Alzheimer's Society Ambassador.

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.

Life review therapy is different from [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 wellbeing, 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.

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 do not 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 on effectiveness at present, but there is some interest in researching this further (Korte et al., 2012; Webster & Height, 2002; Westerhof & Slatman, 2019).

WHO APPROVES/RECOMMENDS LIFE REVIEW THERAPY?

Life review therapy is an alternative form of talking therapy. It is not currently recommended over other forms of talking therapies.

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 not only to help you remember past events but also to communicate and share your memories and future hopes with people. It can help build connections with others to share memories and support conversations. It can help towards advance care planning.

A life story book often contains photographs or pictures which can help to illustrate your memories and important moments. Technology is developing all the time and there are many ways to do this. For example, 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 wellbeing.
- Life story work can help to support identity and maintain a sense of self.
- 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.

WHAT ARE THE POSSIBLE LIMITATIONS OF LIFE STORY WORK?

Looking back over most people's lives can be an emotional experience, for people with traumatic or difficult histories this could be even harder and may need specialist support.

WHO CAN PROVIDE 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 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?

You can ask for advice on making a life history book from a healthcare professional or [Dementia Café](#).

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

Life story network website: <https://www.lifestorynetwork.org.uk/>

The Alzheimer's Society have Factsheets on life history making: <https://www.alzheimers.org.uk/get-support/publications-factsheets>

WHAT IS THE EVIDENCE FOR LIFE STORY WORK?

There is evidence that production of a life story results in benefits to mood, wellbeing and aspects of cognitive function as well as potential to help with social interactions (Clarke, Hanson & Ross, 2003; Elfrink et al., 2018; Woods & Subramaniam, 2016).

WHO APPROVES/RECOMMENDS LIFE STORY WORK?

Life story work is recommended by the National Institute of Health and Care Excellence and the Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE) Guidelines NG97, Standard 1.4.1 (National Institute of Health and Care Excellence, 2018)

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme* (MSNAP) Standards, Standard 187.

Contributed by Polly Kaiser, Consultant Clinical Psychologist, Pennine Care NHS Trust.

Meeting centres

WHAT IS A MEETING CENTRE?

A meeting centre is a local resource, operating out of ordinary community buildings, that offers on-going warm and friendly expert support to people and families affected by dementia. At the heart of the meeting centre is a social club where people meet to have fun, talk to others, and get help that focuses on what they need.

WHO IS A MEETING CENTRE FOR?

A meeting centre is for people affected by mild to moderate dementia and their families.

WHAT GOES ON IN A MEETING CENTRE, AND HOW DOES IT WORK?

A team of staff and volunteers trained in the meeting centre ethos provide an enjoyable and flexible programme for both the person with dementia and their family. The social club meets regularly with around 15–20 members per day. Everyone brings their skills and talents to the meeting centre and the programme is driven by what people want to do. People attend as little or as often as they want. The meeting centre supports people (members and family members) in helping them cope with the consequences of living with dementia and to make the best possible lifestyle adjustments for them as individuals.

- Meeting centres help people to understand their changing symptoms. It offers practical, emotional, and social support and keeps people in touch with professional services.
- The programme contains elements known to support the health and wellbeing of members. This involves a chance to get together socially, to be creative, to get active and to share lunch.
- Family members get assistance with practical and emotional issues, as well as being able to contribute to social club activities. Some family members use the opportunity to have a break from their caring role, some enjoy the club together.
- Couples' consulting sessions, social activities and excursions also help people to enjoy life together.

HOW LONG WOULD I GO TO A MEETING CENTRE FOR?

Meeting centres are open from between one day and three days per week. People can attend as little or as often as they wish, and for as long as they wish.

WHAT BENEFITS MIGHT I SEE FROM USING A MEETING CENTRE?

There is good evidence both from Dutch research and recent UK research that people attending meeting centres experience better self-esteem, greater feelings of happiness and sense of belonging than those who do not attend. Those who attended most regularly showed fewer of the more distressing symptoms of dementia and a greater feeling of support. Family members also experience less burden and feel better able to cope. People with dementia and family members report high levels of satisfaction with the programme, seeing it as an important way of keeping active and feeling supported.

WHAT ARE THE POSSIBLE LIMITATIONS TO USING MEETING CENTRES?

At the moment, there are a limited number of meeting centres around the UK. The UK Meeting Centres Support Programme aims to help communities establish meeting centres across the UK.

WHO PROVIDES MEETING CENTRES?

Meeting centres are provided as part of local community initiatives. It could be organised by a charity who employs a manager and staff including volunteers or it could be an existing club, such as a sports club, or in the early stages it might be a group of volunteers.

WHERE CAN I ACCESS A MEETING CENTRE? (HOW DO I JOIN THESE GROUPS?)

To find out if there is a meeting centre in your area ask your dementia adviser, or look on the Association of Dementia Studies website: <https://www.worcester.ac.uk/discover/uk-meeting-centres-support-programme.html> or email meetingcentres@worcs.ac.uk. Ask your dementia adviser to put you in touch with the meeting centre or you could contact the meeting centre directly.

WHERE CAN I FIND MORE INFORMATION ABOUT MEETING CENTRES FOR MYSELF?

Further information about meeting centres can be found on the Association of Dementia Studies website: <https://www.worcester.ac.uk/discover/uk-meeting-centres-support-programme.html> and the MeetingDem website: <https://www.meetingdem.eu>

WHAT IS THE EVIDENCE FOR MEETING CENTRES?

Initial research suggests that meeting centres supported mood, self-esteem, and a sense of belonging for people living with dementia, and improved mental health for family members (Brooker, Dröes & Evans, 2017; Brooker et al., 2018; Evans et al., 2018).

WHO APPROVES/RECOMMENDS MEETING CENTRES?

Meeting Centres are relatively new in the UK and there is growing evidence for the need for and benefit of them. However, as this is a newly emerging area of research, there is no formal recommendation for them at present. They are currently overseen by a reference group of experts in the field. The National Institute of Clinical Excellence recommends that a range of activities are offered to promote wellbeing, tailored to personal preference (NICE, 2018).

Section contributed by Dr Shirley Evans, Senior Research Fellow, Association for Dementia Studies, University of Worcester.

Museums, arts galleries and heritage sites

WHAT ARE MUSEUM-BASED PROGRAMMES?

There are over 2000 museums, art galleries and heritage sites in the UK and taken together, they offer a tremendous public health resource for the entire nation. Many are free to attend or charge only a modest amount for specific activities. An increasing number of them offer programmes for people with dementia, their family, and friends.

WHO ARE MUSEUMS FOR? WHY GO TO A MUSEUM?

Museums, galleries, and heritage sites *are for everyone* and everyone should feel welcomed, valued, and appreciated when attending. If you are looking for a programme, go to the information desk, where someone will direct you.

Programmes for people with dementia, their families and friends are designed to provide motivating experiences that are enjoyable and help to maintain meaning in life, interest, wellbeing and just the right amount of stimulation and challenge. They are places to attend as an individual or with others.

WHAT DO THESE PROGRAMMES AND ACTIVITIES DO?

Programmes in museums usually take place in small groups and may involve looking at and discussing art; handling museum objects; looking at art or objects and then painting them or a combination of these. They are **not designed to test your knowledge, nor do they expect you to know anything about art**; they are designed to allow you to have an enjoyable experience for learning and social participation.

HOW LONG ARE PROGRAMMES THAT TAKE PLACE IN MUSEUMS?

Sessions usually last between one and two hours and may offer refreshments. Some offer ongoing programmes over a few weeks once a month or are focused on an exhibition or theme.

WHAT BENEFITS MIGHT I SEE FROM ATTENDING A MUSEUM, ART GALLERY OR HERITAGE PROGRAMME?

Museums, galleries, and heritage sites offer places to visit that are visually and intellectually stimulating and provide an environment that allows you to learn about the world and yourself. Attending a specific programme or just visiting a venue may also offer you the following:

- learning something new just for the joy of it
- improving wellbeing and quality of life
- having an interesting 'in the moment' experience
- visiting a place with set hours so you know when they are open, a welcoming atmosphere, a café to relax in and the freedom to discover and wander about

WHAT ARE THE POSSIBLE LIMITATIONS?

People may need to travel outside their immediate area to attend these venues. Not all museums are free to visit and there may be a cost to some of these programmes.

WHO CAN OFFER THESE PROGRAMMES?

People who facilitate programmes at art galleries, museums and heritage sites can be professional guides, curators, museum educators, art historians and community outreach specialists; they also may be trained volunteers who have been carefully chosen by the organisation.

WHERE CAN I FIND MORE INFORMATION ABOUT MUSEUMS, ART GALLERIES AND HERITAGE SITES FOR MYSELF?

If you have access to the internet, try looking up local cultural organisations to see what they offer in the way of classes, community outreach and tours (art galleries and museums).

You may also want to contact the following organisations for information:

The Alzheimer's Society offers a guide to dementia friendly heritage sites: <https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/organisations/dementia-friendly-heritage-sites>

Arts 4 Dementia offers a list of organisations offering activities: <https://arts4dementia.org.uk/welcome-to-a4d/>

Many of these programmes occur in museums (<https://www.museumsassociation.org/home>).

The Elder Magazine has an informative article about art galleries, museums and dementia: <https://www.elder.org/the-elder/displaying-inclusivity-responding-to-visitors-with-dementia/>

WHAT IS THE EVIDENCE FOR MUSEUMS, ART GALLERIES AND HERITAGE?

There is increasing evidence from studies in the UK and internationally that arts-based and other cultural and heritage programmes can reduce adverse psychological and physiological symptoms and are positive places for wellbeing, enhancing cognition and self-reported health, in addition to helping people feel less socially isolated. There has also been specific research showing that handling and discussing museum objects can benefit wellbeing, new learning, confidence, and optimism (Camic et al., 2017; MacPherson et al., 2009; Young et al., 2015).

WHO RECOMMENDS MUSEUM AND CULTURAL ACTIVITIES?

Age UK recommends that cultural activities can enhance wellbeing later in life (Age UK, 2018).

The Alzheimer's Society suggests arts and cultural activities in the community offer a chance to meet others and participate in an enjoyable activity that is intellectually stimulating (Alzheimer's Society, n.d.).

Section contributed by Prof Paul Camic, Honorary Professor of Health Psychology, Dementia Research Centre, University College London.

Music therapy

WHAT IS MUSIC THERAPY?

Music therapy is one of the four arts therapies, (the other three are drama, art, and dance). It is based on the principle that: 'The ability to appreciate and respond to music is an inborn quality in human beings. This ability usually remains unimpaired by dementia and is not dependent on musical training' (British Association of Music Therapy). Music therapy sessions can be with individuals or groups. The music therapist will use singing and music to find ways of interacting with you and to form a therapeutic relationship.

WHAT DOES MUSIC THERAPY INVOLVE? HOW DOES IT WORK?

Music therapy sessions usually consist of singing and improvised music. People sing from memory or song-sheets, sometimes using percussion instruments. Each session is structured by the therapist, and people are encouraged to contribute as much or as little as they choose. For example, you may prefer to sit quietly and listen, to join in with the singing, to choose songs for the group, to reminisce about the reason a particular song is special to you, to lead a group improvisation through starting a rhythmic pulse on a tambourine, or to create sound effects using the instruments to enhance the songs. Or all of these! If you do play a musical instrument or enjoy singing solos, space will be created for you to use your skills. Each session is guided by the needs of those attending. The sessions are often lively and fun. Sometimes, however, you may need a good cry, and if you need it, support will be offered.

WHO IS MUSIC THERAPY FOR?

Music therapy can be for anyone who feels that interaction with music can improve their wellbeing 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?

Group sessions usually last about an hour. Individual sessions can be tailored according to the length of time preferred by the person. Sessions are usually once a week, but again this can be individually arranged between the person, relatives, and therapist. Sessions may be ongoing or fixed for a specific period of time.

WHAT BENEFITS MIGHT I SEE FROM HAVING MUSIC THERAPY?

Evidence suggests that by engaging with the healthy parts of a person's brain, music therapy may help to alleviate some of the effects of dementia, including loss of confidence, low self-esteem, depression, frustration, irritability, and anxiety.

Music therapy is a creative, interactive activity and as such it may help to promote and increase opportunities for social interaction. As well as being a physically stimulating activity, music making and singing, with a trained therapist offers opportunities to express emotions and feelings in a safe environment. Sharing of memories, through music may also help to reconnect the person with their life experiences and strengthen their sense of identity.

WHAT ARE THE LIMITATIONS OF MUSIC THERAPY?

Music therapy requires a specifically trained music therapist and may not be provided in your area. Most music therapists working in the field of dementia in the UK are employed to work in care homes or hospital wards, so if you live in the community you may need to employ a music therapist on a private basis.

WHO CAN OFFER ME MUSIC THERAPY?

Music therapy can be provided by trained music therapists.

WHERE CAN I ASK FOR MUSIC THERAPY?

Music therapists can be found working within multidisciplinary teams in hospitals, day centres, hospices, care homes, therapy centres and in private practice across the UK. You may 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.

If you are interested in accessing music therapy privately, the British Association of Music Therapy can help you to find a music therapist and advise on access to music therapy in your area:

www.bamt.org

The book *Music Therapy in Dementia Care* provides an overview of the role of music therapy in caring for people with dementia in a range of settings.

WHAT IS THE EVIDENCE FOR MUSIC THERAPY?

Evidence suggests that music therapy has a positive effect on anxiety, depression, quality of life, cognitive function, and behaviour that challenges, but emphasises that the intervention should be delivered by a therapist with a formal music therapy qualification. Additionally, some studies suggest that memory for information is improved when the information is presented in the context of a song (Gould, 2015; van der Steen et al., 2018; Zhang et al., 2017.)

WHO APPROVES/RECOMMENDS MUSIC THERAPY?

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

Royal College of Psychiatrists (2020). Memory Services National Accreditation Programme (MSNAP) Standards, Standard 191.
British Psychological Society (2014). *Clinical psychology in the early-stage dementia care pathway*.

Section contributed by Ian Spink, Music Therapist, Kent and Medway NHS Partnership Trust.

Occupational therapy

WHAT IS OCCUPATIONAL THERAPY?

Occupational therapy aims to improve people's health and wellbeing through participation in occupations, everyday activities people want and need to be able to do.

An occupational therapist can:

- help you to keep doing the occupations you value.
- advise on the best ways to maintain your skills, routines, and roles.
- adapt your home to make life easier and improve safety.
- advise on technology that can help you to remain independent.

An occupational therapist will consider all your needs – physical, psychological, social, and environmental. They will work with you to agree goals and work towards getting a balance between your choices and managing any concerns or risk.

WHO IS OCCUPATIONAL THERAPY FOR?

Occupational therapy is aimed at anyone with a diagnosis of dementia and their supporters who might be struggling to engage in and maintain valued activities of daily living.

WHAT DOES OCCUPATIONAL THERAPY INVOLVE? HOW DOES OCCUPATIONAL THERAPY WORK?

Occupational Therapists can suggest alternative ways of carrying out activities; provide advice on learning new approaches, with the aim of helping people to maximise their potential. For example, an Occupational Therapist can help people with the following:

- Self-care – e.g. getting dressed, preparing, and eating meals.
- Productivity – e.g. remaining in work, volunteering, studying, or caring for others.
- Leisure – e.g. playing sports, carrying out interests and hobbies.

HOW LONG DOES OCCUPATIONAL THERAPY TAKE?

Your occupational therapist will talk to you about your goals and how these might be addressed over one or several sessions. There may be a time limit depending on provision in your area.

WHAT BENEFITS MIGHT I SEE FROM OCCUPATIONAL THERAPY?

- Being able to continue to participate in the occupations you value.
- Family or professional carers feeling more confident in supporting you to continue to participate in daily life.
- Improved confidence and maintaining your independence.
- Living in a home environment that is safe and works for you.
- Improved sense of wellbeing, reduced feelings of distress.

WHAT ARE THE POSSIBLE LIMITATIONS OF OCCUPATIONAL THERAPY?

Working with your occupational therapist is a two-way process which aims to understand what is important to you and achieve the best possible outcome. It is therefore important to be open and honest about your strengths and difficulties as a family member or as a person living with dementia in order to engage fully.

WHO CAN PROVIDE ME WITH OCCUPATIONAL THERAPY?

A trained Health and Care Professions Council (HCPC) registered occupational therapist.

WHERE CAN I ASK FOR OCCUPATIONAL THERAPY?

You can ask for a referral for occupational therapy through your memory service, community mental health service, local authority, or GP. There are also private occupational therapists.

WHERE CAN I FIND MORE INFORMATION ABOUT OCCUPATIONAL THERAPY?

You can find out more information about occupational therapy from the Royal College of Occupational Therapists: www.rcot.co.uk

WHAT IS THE EVIDENCE FOR OCCUPATIONAL THERAPY?

There is some evidence that occupational therapy can be beneficial for people with dementia (Bennett et al., 2019; Graff et al., 2006; McLaren et al., 2013).

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) Guidelines NG97, Standard 1.4.4 (National Institute of Health and Care Excellence, 2018).

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme (MSNAP) Standards*, Standard 179.

Section contributed by Alice Moody, Clinical Specialist Occupational Therapist, Gloucestershire Health and Care NHS Foundation Trust, and Emma Barton, Head Occupational Therapist, Central and Northwest London Foundation Trust.

Participatory arts

WHAT ARE THE PARTICIPATORY ARTS?

According to the Tate Gallery, 'Participatory art is a term that describes a form of art that directly engages the audience in the creative process so that they become participants in the event.' It is an approach to the arts that encourages the public's participation, together with professional artists, in the creative process of making art be it poetry, painting, collage, singing, ceramics, dance, drama or other art forms.

WHO ARE THE PARTICIPATORY ARTS FOR?

Participatory arts are for anyone, but there are some participatory arts activities specifically for people with dementia. Participatory arts offer experiences to engage in the arts with professional artists, singers, musicians, poets, actors, and other creative professionals. Most activities occur within a group, but some one-to-one experiences are possible too.

WHAT DO PARTICIPATORY ARTS INVOLVE? HOW DOES IT WORK?

Through engagement in an arts activity, such as poetry, painting, collage, singing, ceramics, dance or drama, people have the opportunity to express themselves in a non-medical environment. It aims to create enjoyable experiences, to take part 'in the moment' of a creative activity, to work towards a display, performance or to co-curate.

HOW LONG DO PARTICIPATORY ARTS PROGRAMMES LAST?

Individual or group sessions of participatory arts programmes last for an hour or two. Courses or programmes usually run for a number of weeks.

WHAT ARE THE BENEFITS OF PARTICIPATORY ARTS?

Engagement in arts activities can enhance relationships with family members and friends, enable creativity, reduce social isolation, and provide sensory stimulation. Participatory arts have been shown to help individual and community wellbeing.

WHAT ARE THE POSSIBLE LIMITATIONS?

If you have never done these types of activities before, they may feel a little uncomfortable to engage in at first. However, facilitators are usually very good at making people feel at ease and would not make you do anything you do not feel comfortable doing. People may find it helpful to attend with a family member, or someone close to them.

WHO PROVIDES PARTICIPATORY ARTS?

Your local arts organisations, museums, arts for health programmes and charities who provide participatory arts programmes. Please see below for website details of the relevant organisations.

HOW CAN I FIND OUT MORE INFORMATION ABOUT PARTICIPATORY ARTS?

In addition to the resources below, also check your local arts organisations, social services, local councils, and local Age UK and Alzheimer's Society offices.

Arts 4 Dementia website: <https://arts4dementia.org.uk/>

Alzheimer's Society website: <https://www.alzheimers.org.uk/get-support/publications-factsheets>

Created Out of Mind website: <http://www.createdoutofmind.org/>

Age of creativity: <http://www.ageofcreativity.co.uk>

WHAT IS THE EVIDENCE FOR PARTICIPATORY ARTS?

Research in the participatory arts and dementia is only about a decade old but has begun to demonstrate important contributions in the areas of wellbeing, identity, creativity, reduction in aggressive behaviour, quality of life, mood, enhancing relationships and enjoyment. Research has also shown that a previous interest or experience in the arts is not a prerequisite to benefit from participatory arts. Singing research is most prominent across the participatory arts and has some of the most compelling evidence to date (Camic et al., 2018; Osman et al., 2016; Särkämö et al., 2013; Zeilig et al., 2014).

WHO APPROVES/RECOMMENDS PARTICIPATORY ARTS?

National Institute of Health and Care Excellence (NICE) Guidelines NG97, Standards 1.1.12 and 1.1.13 (National Institute of Health and Care Excellence, 2018)

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme (MSNAP) Standards*, Standard 151, 154.

Section contributed by Prof Paul Camic, UCL Dementia Research Centre, and Veronica Gould, Founder and President, Arts 4 Dementia.

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 with each other. Some peer support groups also run online, for example in rural areas or meeting internationally.

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 friends and/or family.

WHAT DOES A PEER SUPPORT GROUP DO? HOW DO THEY WORK?

Group members share practical hints and tips on day to day living with dementia. People discuss what they find difficult and how they overcome challenges. Often just sharing a problem or knowing someone else has felt the same way can make the problem feel more manageable.

HOW LONG DOES PEER SUPPORT TAKE?

Some groups meet for a set period of time, for example once a week for six weeks. Groups may meet for one or two hours each session.

Other groups are ongoing, meeting weekly or monthly as members decide. There are online forums that are open 24/7.

WHAT BENEFITS MIGHT I SEE FROM JOINING A PEER SUPPORT GROUP?

You may feel differently once you meet others in a similar situation.

This may lead to:

- increased confidence
- reduced isolation
- reduced depression
- increased quality of life

WHAT ARE THE LIMITATIONS OF PEER SUPPORT GROUPS?

It is hoped that by joining a group you will meet people who understand and have similar experiences to yourself. However, you may not feel like sharing at first. You may not feel the others in the group are similar to you at all. For example, people with young onset dementia may have different problems from the majority. In the group there may be people living with a range of types and severities of dementia, different from yourself.

WHO CAN PROVIDE PEER SUPPORT GROUPS?

Some peer support groups are organised by people with dementia or by family members. Other groups can be supported by a healthcare professional or hosted by a charity. There are also peer support groups offered by faith communities.

WHERE CAN I ASK TO JOIN A PEER SUPPORT GROUP?

Some groups are referral only, for example through your local memory service. Many groups are open to anyone with a diagnosis and any professional involved in your care may be able to signpost you.

WHERE CAN I FIND MORE INFORMATION ON PEER SUPPORT GROUPS FOR MYSELF?

You can ask any professional involved in your care about peer support groups available in your local area.

You can also find details about peer support groups from the following websites:

DEEP: <https://www.dementiavoices.org.uk/deep-groups/>

Dementia Alliance International: <https://www.dementiaallianceinternational.org/services/online-support-groups/>

You can also use an online search engine to search for 'dementia peer support groups'.

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 (Keyes et al., 2016; Logsdon et al., 2010; Willis et al., 2018).

WHO APPROVES/RECOMMENDS PEER SUPPORT GROUPS?

Peer support groups for people living with dementia are recommended by the Royal College of Psychiatrists:

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme (MSNAP) Standards*, Standard 141.

Section contributed by Chris Roberts, Vice Chair, European Dementia Working Group, and Jayne Goodrick, wife and carer.

Post-diagnostic counselling

WHAT IS POST-DIAGNOSTIC COUNSELLING?

Post-diagnostic counselling is a process of providing information and support to help you adjust to your diagnosis of dementia. It also involves thinking about your needs and working out the next steps. It can involve individual sessions at your memory service, usually offered soon after a diagnosis, giving you an opportunity to discuss the diagnosis and how you feel about it, to ask any questions you may have at that point in time, and to learn about other services and sources of support available to you.

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 feel ready. Many find it useful to have a partner, relative or friend attend with them.

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. There may be a waiting list.

WHO CAN PROVIDE ME WITH POST-DIAGNOSTIC COUNSELLING?

Many healthcare professionals can provide post-diagnostic counselling, as long as they have had training. It can be provided by a professional at your memory service (for example, a psychiatrist, nurse, psychologist, or support worker). It might be offered by the voluntary sector, or be a part of other interventions you are involved in.

WHERE CAN I ASK FOR POST-DIAGNOSTIC COUNSELLING?

Post-diagnostic counselling is an important part of the diagnostic process and should be offered around the time 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?

A book by Moniz-Cook and Manthorpe (2009) gives an overview of the factors that should be a part of post-diagnostic counselling and explains how individual needs can still be met with limited resources.

Post-diagnostic counselling can take many forms and is tailored to individual preferences. It has therefore not been studied in the same way as many other interventions. However, some evidence suggests that post-diagnostic counselling can have a significant benefit to wellbeing, when combined with pre-diagnostic counselling (Jha et al., 2012).

WHO APPROVES/RECOMMENDS POST-DIAGNOSTIC COUNSELLING?

Post-diagnostic counselling for dementia is recommended by the British Psychological Society and the Royal College of Psychiatrists. Information and support is recommended by NICE as part of ongoing management.

National Institute of Health and Care Excellence (NICE) Guidelines NG97, Standards 1.1.4 and 1.1.6 (National Institute of Health and Care Excellence, 2018).

Royal College of Psychiatrists (2020). Memory Services National Accreditation Programme (MSNAP) Standards, Standards 139, 140.

British Psychological Society (2014). *Clinical psychology in the early-stage dementia care pathway*.

Section contributed by Prof Rik Cheston, Professor of Dementia Research, University of the West of England.

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 course, you will have the opportunity to learn and talk about many relevant subjects:

- 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 4–12 sessions, with one session per week for up to two hours.

WHAT BENEFITS MIGHT I SEE FROM JOINING A POST-DIAGNOSTIC GROUP OR COURSE?

- Talk more openly about the diagnosis and what it means.
- Feel more able to cope with a diagnosis.
- Realise that you are not on your own – meet others in a similar situation.
- Learn about your memory.
- Think about ways to manage your symptoms of dementia.
- Increase your confidence and wellbeing.
- Give you a greater sense of belonging and purpose.

WHAT ARE THE POSSIBLE LIMITATIONS OF POST-DIAGNOSTIC GROUPS OR COURSES?

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, are much younger than most group members or have been diagnosed with dementia in very early stages, a generic course may not meet your needs. While the great benefit of post-diagnostic courses comes from meeting others in a similar position to you, sometimes this can bring home to people the reality of their diagnosis. Often people are concerned that they will meet someone with more severe problems than they have.

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 and public venues, such as your local memory service, or community centre. After you have been given a diagnosis, you may be offered referral to a group or a course. 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 care for someone living with dementia, you can find support at: <https://www.alzheimers.org.uk/about-us/our-dementia-programmes/carer-information-support-programme>

WHAT IS THE EVIDENCE FOR POST-DIAGNOSTIC GROUPS?

Evidence suggests that post diagnostic groups can help with quality of life, mood, family communication, and self-esteem (Logsdon et al., 2010; Moniz-Cook & Manthorpe, 2009).

WHO APPROVES/RECOMMENDS POST-DIAGNOSTIC GROUPS?

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme (MSNAP) Standards*, Standards 139, 140.
British Psychological Society (2014). *Clinical psychology in the early-stage dementia care pathway*.

Section contributed by Prof Rik Cheston, Professor of Dementia Research, University of the West of England.

Reminiscence/reminiscence therapy

WHAT IS REMINISCENCE/REMINISCENCE THERAPY?

Reminiscence, sometimes known as reminiscence therapy, is an activity which involves remembering and retelling memories from your past, and events from your life, often aided by looking at materials from a particular time. It is more general and informal than life story work and life review therapy.

WHO IS REMINISCENCE THERAPY FOR?

Reminiscence is for anyone, in particular those with a diagnosis of dementia.

WHAT DOES REMINISCENCE THERAPY DO? HOW DOES IT 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 use of general prompts such as photos, objects, or music from that time. Reminiscence therapy can use all the senses (such as taste or smell) in order to evoke different memories.

Reminiscence uses a person's past memories, rather than focusing on the here and now, or talking about the disability caused by dementia.

You may talk about the following things during reminiscence sessions:

- childhood, school days and 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 THERAPY 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 THERAPY?

Attending regular reminiscence sessions may give you the following benefits:

- improved cognitive function
- improved quality of life
- a better understanding of your identity
- if done in a group, this can also include the benefits associated with social interaction

WHAT ARE THE POSSIBLE LIMITATIONS TO REMINISCENCE THERAPY?

Unpleasant memories may be brought up, causing discomfort. However, a good facilitator should be able to handle such issues sensitively.

WHO CAN SUPPORT ME WITH REMINISCENCE THERAPY?

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

WHERE CAN I ASK FOR REMINISCENCE THERAPY?

Your memory service may run reminiscence groups. Alternatively, there may be groups local to you which are run by third sector organisations.

WHERE CAN I FIND MORE INFORMATION ABOUT REMINISCENCE THERAPY FOR MYSELF?

Information can be provided by health care professionals.

WHAT IS THE EVIDENCE FOR REMINISCENCE THERAPY?

There are few studies looking at the effectiveness of reminiscence therapy, and these are often small in scale. While there is a need for more studies and larger-scale research, the available evidence at the time of publication suggests that reminiscence therapy has a positive effect on mood and cognition (Cotelli et al., 2012; Woods et al., 2005).

WHO APPROVES/RECOMMENDS REMINISCENCE THERAPY?

Reminiscence is recommended by the British Psychological Society, the National Institute of Health and Care Excellence, and the Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE) Guidelines NG97, Standard 1.4.3.

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme (MSNAP) Standards*, Standard 186.

British Psychological Society (2014). *Clinical psychology in the early-stage dementia care pathway*.

Section contributed by Prof Rik Cheston, Professor of Dementia Research, University of the West of England.

Signposting

WHAT IS SIGNPOSTING?

Effective 'signposting' is when you are given timely information and are referred to relevant services by someone who understands your needs and what services are available.

For example, you may wish to know about a specific psychosocial intervention, and they will be able to provide you with the relevant information and how to access that support.

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 and referrals are 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.

You may be given the information you want for the questions you have at the moment. Information should be available to you throughout your contact with professionals, and therefore signposting is an ongoing process.

HOW LONG DOES SIGNPOSTING TAKE?

Most information can be given to you 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?

- Greater information can answer some of the many questions that you and your family may have 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.
- Knowing where to access support and that there is support available may increase your confidence and decrease your stress by reducing uncertainty.

WHAT ARE THE POSSIBLE LIMITATIONS OF SIGNPOSTING?

There may not be any or enough information available in written form relating to your specific questions. If you do not use a computer, some online information may be inaccessible to you. It is also crucial that you are signposted to the right information at the right times. Being given too much information all at once may feel overwhelming. You may find more specific information as well as signposting through specialist advice or post-diagnostic counselling.

WHO PROVIDES SIGNPOSTING?

A professional such as your care coordinator, mental health nurse, occupational therapist or psychologist at the memory service can direct you towards useful information. Specialist helplines nationally and locally also offer signposting. There may also be local dementia advisors.

WHERE CAN I ASK FOR SIGNPOSTING?

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 Alzheimer's Society, or Age UK dementia outreach worker or 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 by talking to a professional at the memory service, or through a dementia advisor.

You can also receive information through the voluntary sector organisations:

Alzheimer's Society National Dementia Helpline: 0300 222 1122

website: <http://www.alzheimers.org.uk>

Age UK telephone: 0800 169 6565

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

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

WHAT IS THE EVIDENCE FOR SIGNPOSTING?

Much of the evidence for signposting comes from what people living with dementia have said about their experience of diagnosis, and about the benefits of being helped to find support after diagnosis (Hagan, 2020; Clarke et al., 2013). Studies have defined signposting differently and used different measures for their benefits (Corbett et al., 2012).

WHO APPROVES/RECOMMENDS SIGNPOSTING?

Signposting is recommended by the National Institute of Health and Care Excellence and the Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE) Guidelines NG97, Standard 1.1.6.

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme* (MSNAP) Standards, Standard 162.

Social and therapeutic horticulture

WHAT IS SOCIAL AND THERAPEUTIC HORTICULTURE?

Social and therapeutic horticulture, sometimes called horticulture therapy, is the use of gardens and plants to support health and wellbeing. It is a broad description of a variety of approaches making the most of gardens and nature.

It makes the most of time in nature, in a social group and being active. It can be as short and simple as taking a minute to appreciate the sensory nature of a plant or as long as developing a garden over a season or years. Working alongside a skilled practitioner acting as a guide and supporting the participant can maximise benefits.

WHO IS SOCIAL AND THERAPEUTIC HORTICULTURE FOR?

Anyone with dementia could benefit and some programmes could be supportive of friends and/or family.

HOW DOES SOCIAL AND THERAPEUTIC HORTICULTURE WORK, WHAT IS INVOLVED?

Social and therapeutic horticulture can take place in a variety of settings, for example, community gardens, care settings, at home or even indoors. Gardens of all sizes and types can be used although specifically designed gardens can work even better. It focuses on what a person can do, not what they cannot. The practitioner engages with each person to understand their affinity for nature (what they love or do not like about plants and gardens). They arrange meaningful garden related activities and experiences to meet people's physical, sensory, social, and cognitive strengths.

HOW LONG DOES A SOCIAL AND THERAPEUTIC HORTICULTURE ENGAGEMENT TAKE?

Each session could be as short as a few minutes or as long as several hours. It can be beneficial over short periods or over a number of years. With passion and training, family and friends can easily continue to provide some of the values of social and therapeutic horticulture.

WHAT BENEFITS MIGHT I EXPECT FROM SOCIAL AND THERAPEUTIC HORTICULTURE?

The benefits can be very holistic, supporting physical, sensory, psychological, emotional, and social wellbeing. There are benefits of connecting to other living things and making a difference to life around you, such as the plants or vegetables you grow. There are also social benefits in sharing the enjoyment of the garden with others.

WHAT ARE THE LIMITATIONS OF SOCIAL AND THERAPEUTIC HORTICULTURE?

Some people can be allergic to elements of gardens and plants and may experience hay fever.

Some gardening equipment and materials can be hazardous.

The evidence base is still limited, with more evidence to support its effectiveness for mental health than for people with dementia.

WHO CAN PROVIDE ME WITH SOCIAL AND THERAPEUTIC HORTICULTURE?

You can find organisations in the community providing Social and therapeutic Horticulture, some community gardens also have programmes designed to be suitable for people with dementia. Local dementia services and your GP may know of community projects close to you. However, where organised activities are not available, spending time gardening or in gardens can also be beneficial.

WHERE CAN I FIND OUT MORE INFORMATION?

Thrive, the Society for Horticulture Therapy have a range of information and resources that can help people. <https://www.thrive.org.uk/>

Social farms and gardens <https://www.farmgarden.org.uk/>

Dementia Adventure is an organisation that uses nature in a wider context to support people with dementia to live well, they offer shorter experiences like gardening and nature walks alongside holidays in rural and wilderness locations <https://dementiaadventure.co.uk/>

WHAT EVIDENCE IS THERE FOR SOCIAL AND THERAPEUTIC HORTICULTURE?

Current research on the benefits of social and therapeutic horticulture is small-scale, but suggests that gardening can help with emotions such as low mood or anxiety. Studies suggest that it can provide stimulation, a sense of freedom and ownership, and the opportunity to connect with memories and with others, in addition to the benefits of light exercise and being outside (Lu et al., 2020; Buck, 2016; Clark, Mapes, Burt & Preston, 2013).

WHO APPROVES/RECOMMENDS SOCIAL AND THERAPEUTIC HORTICULTURE?

Social and therapeutic horticulture is recommended under the NHS green social prescribing scheme:

<https://www.england.nhs.uk/personalisedcare/social-prescribing/green-social-prescribing/>

The Alzheimer's society also recommends:

https://www.alzheimers.org.uk/sites/default/files/2018-05/AS_Designing_Garden_Guide_Web.pdf

It is also recommended by the National Institute of Health and Care Excellence.

National Institute of Health and Care Excellence (NICE) Guidelines NG97, Standard 1.4.1.

Section contributed by Damian Newman, Training, Education and Consultancy Manager, Thrive.

Specialist services for younger people with dementia

WHAT ARE SPECIALIST SERVICES FOR YOUNGER PEOPLE WITH DEMENTIA?

In the UK, the term 'young onset dementia' typically refers to people diagnosed with dementia under the age of 65. Although people with young onset dementia can experience similar symptoms to older people with dementia, the impact on their lives can be very different. This is often because people of this age group are still of working age, and this has financial implications. They are also more likely to have caring responsibilities themselves, either for young children or elderly parents. For this reason, there is a need for specialist services to provide advice and support specific for a younger age group.

WHO ARE SPECIALIST SERVICES FOR YOUNGER PEOPLE WITH DEMENTIA FOR?

These services are designed for younger people with dementia, as well as family members and any others in their support network.

WHAT DO SPECIALIST SERVICES FOR YOUNGER PEOPLE WITH DEMENTIA INVOLVE? HOW DO THEY WORK?

Many of the other interventions in this guide can and have been adapted for people with young onset dementia. In particular, some regions have services providing [CST](#), [peer support](#), [post-diagnostic counselling](#) and [post-diagnostic groups](#) specifically for younger people. For example, CST might be adapted by providing more physically active activities, and reminiscence from a more recent time period. Post-diagnostic counselling/groups might involve discussions around work and different benefit entitlements to those of retirement age.

HOW LONG DO THESE SERVICES TAKE?

This depends on the type of service being offered, as well as your individual need.

WHAT BENEFITS MIGHT I SEE FROM ACCESSING THESE SERVICES?

Services designed to meet the needs of younger people with dementia are likely to be more relevant and useful than similar services designed for older people. Receiving a diagnosis of dementia at a young age can feel isolating, as it is relatively rare. Accessing specialist interventions, particularly if they are in a group format, can help to reduce feelings of isolation.

WHAT ARE THE POSSIBLE LIMITATIONS OF THESE SERVICES?

Availability of specialist interventions may be limited, depending on your area. Because these services are rarer, you may not have as much choice as older people in which interventions or groups you are offered.

WHO CAN PROVIDE ME WITH THESE SERVICES?

Services may be provided by your local memory/dementia assessment service, or by the private or voluntary sector. Your memory clinic should be able to advise you on this, even if they do not offer the services themselves.

WHERE CAN I ASK FOR THESE SERVICES?

Aside from local memory clinics, there are a number of online resources:

The Young Dementia UK website has a directory of known services for younger people across the UK: <https://www.youngdementiauk.org/support-across-uk>

WHERE CAN I FIND MORE INFORMATION ON THESE SERVICES?

Young Dementia Network provides information, resources, and ways of becoming involved with the young dementia network: <https://www.youngdementiauk.org/young-dementia-network>

The Alzheimer's Society has a section with information, advice and where to access further support:

https://www.alzheimers.org.uk/info/20007/types_of_dementia/17/young-onset_dementia

WHAT IS THE EVIDENCE FOR SPECIALIST SERVICES FOR YOUNGER PEOPLE WITH DEMENTIA?

To date, there are few studies looking into the benefits of specialist services for younger people. This is partly due to a current lack of such services. The ANGELA project (Parkes et al., 2018) is using various methods to develop evidence-based guidance for improving diagnosis and post-diagnostic support for younger people with dementia. A recent review of the literature found that services specifically for younger people with dementia enabled them to remain at home for longer (Mayrhofer et al., 2017).

WHO APPROVES/RECOMMENDS SPECIALIST SERVICES FOR YOUNGER PEOPLE WITH DEMENTIA?

The Memory Services National Accreditation Programme (MSNAP) recommends that interventions offered after a diagnosis of young onset dementia are age appropriate, including younger age groups.

Memory Services National Accreditation Programme (MSNAP) Standards, Standards 167, 180, 184 (Royal College of Psychiatrists, 2020).

Specialist support (rare dementias)

WHAT IS MEANT BY SPECIALIST SUPPORT?

There are over 100 types of dementia, some of which are very rare. Specialist services can provide support for the particular challenges faced when a rare form of dementia becomes a part of your life. Support can be provided specifically when these challenges arise, or over the course of your condition. Support is provided by individual trained specialists (e.g. a clinical psychologist, neurologist, occupational therapist, or psychiatrist), and services such as rare dementia support which offer multiple types of support to both people living with a rare dementia, and family members.

WHO IS SPECIALIST SUPPORT FOR?

People diagnosed with less common forms of dementia, and those supporting them. Some examples of these are:

- Frontotemporal dementia (FTD) – a group of dementias predominantly affecting behaviour and personality, some of which have a genetic component.
- Posterior Cortical Atrophy (PCA) – a progressive condition predominantly affecting visual and spatial perception.
- Primary Progressive Aphasia (PPA) – a group of dementias predominantly affecting language skills such as comprehension.
- Lewy Body Dementia (LBD) – a less common form of dementia that is closely related to Parkinson's Disease, predominantly affecting movement and which may include visual hallucinations.
- Young onset or familial Alzheimer's Disease – where symptoms start in people of working age (before 65), or where it is inherited.

WHAT DOES THIS SPECIALIST SUPPORT INVOLVE? HOW DOES IT WORK?

Accessing support services often involves an initial consultation with a professional to determine your support needs. You can discuss your experiences with the professional directly or include your family in the conversation.

The professional will work with you to respond to needs you have identified together:

- sending you information as requested, tailored to your needs
- providing emotional support
- suggesting ways to understand, overcome and/or navigate specific challenges
- putting you in touch with other people with similar experiences.

As well as answering specific questions about your condition, further advice on other services available can be discussed.

HOW LONG CAN I ACCESS SPECIALIST SUPPORT FOR?

This will differ across services. For some specific support needs, the professional may meet you as and when you need specialist input, or there may be a particular support programme length (e.g. an online support course running for four weeks). Some services are able to respond to different support needs

as and when they arise, from helping to navigate initial diagnosis, to supporting family members in bereavement.

WHAT BENEFITS MIGHT I SEE FROM RECEIVING SPECIALIST SUPPORT?

- Specialist professionals are aware of how your experience with a rare dementia may differ to the experiences of those with more common types of dementia.
- Having specialist support and information may help you and your family to plan for the future.
- Services with support group meetings and buddying allow you to connect with families who have similar experiences to your own.

WHAT ARE THE POSSIBLE LIMITATIONS OF SPECIALIST SUPPORT?

Specialist support often involves talking about your condition, sometimes at length. 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 identify post-diagnostic counselling as part of your support needs before or during this process.

WHO CAN PROVIDE ME WITH SPECIALIST SUPPORT?

Specialist support should be available to you from your memory service following your diagnosis of an unusual type of dementia or experience of specific 'non-typical' challenges. In addition to any support you may be receiving locally, you can refer yourself to Rare Dementia Support (RDS); led by the University College London Dementia Research Centre (DRC), available to offer direct support.

WHERE CAN I ASK FOR SPECIALIST SUPPORT?

Specialist information can be accessed online 24 hours a day, seven days a week, by visiting www.raredementiasupport.org. You can contact Rare Dementia Support directly at any point before, during or after you/your loved one receives a diagnosis of a rare dementia. Email contact@raredementiasupport.org or telephone 020 3325 0828 to find out more. Your memory service can also signpost you to specialist support.

WHAT IS THE EVIDENCE THAT SPECIALIST SUPPORT IS HELPFUL?

At the time of publication, there is a large research project being conducted by the UCL Rare Dementia Support Group into the effectiveness of providing specialist support (Brotherhood et al., 2020).

WHO APPROVES/RECOMMENDS SPECIALIST SUPPORT?

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme (MSNAP) Standards*, Standard 180.

Section contributed by Emilie Brotherhood, Senior Research Fellow, Professor Paul Camici and Professor Seb Crutch on behalf of the Rare Dementia Support team, Dementia Research Centre, University College London.

Speech and language therapy (SLT)

WHAT IS SPEECH AND LANGUAGE THERAPY?

Speech and language therapy can be helpful for people throughout the course of their dementia. The speech and language therapist assesses an individual's needs and selects a management approach or intervention that supports effective communication and safe eating and drinking. Speech and language therapists (SLTs) work with both the person with dementia and supporters. SLT assessment can also help with diagnosis, and support issues related to decision-making and mental capacity.

WHO IS SPEECH AND LANGUAGE THERAPY FOR?

People with speech, language and communication or swallowing difficulties at any stage of dementia.

WHAT DOES SPEECH AND LANGUAGE THERAPY INVOLVE? HOW DOES IT WORK?

Speech and language therapy involves specialist assessment to know the best way to help you. This can include looking at changes in your speaking, following what is said, reading and writing.

The SLT will help you understand these changes as well as identifying ways to manage these. SLT often aims at maintaining your communication skills, for example, making a communication book, using aids such as apps on your phone, practicing words or using strategies if you are stuck for a word when speaking (sometimes called 'word-finding' difficulty).

SLT may include working with friends, family, and professionals to communicate on strategies to support you. It can include non-verbal ways of communicating as well as speech. SLTs can support you in understanding and communicating about decisions to do with your care and treatment. Assessment of swallowing can include an observation of you eating and drinking, with the SLT then giving advice on the safest ways to manage food and drink.

HOW LONG DOES SPEECH AND LANGUAGE THERAPY TAKE?

The length, frequency and intensity of therapy depends on different factors and circumstances including your specific needs, your goals, and the aims of intervention.

WHAT BENEFITS MIGHT I SEE FROM SPEECH AND LANGUAGE THERAPY?

- Maintenance of communication skills such as word finding and saying specific sentences.
- Improvements in conversation and maintenance of interpersonal relationships.
- Support to manage changing communication needs over time.
- Support to participate in decisions about care and treatment.
- Support to eat and drink safely and comfortably with reduced risk of choking or pneumonia.

WHAT ARE THE POSSIBLE LIMITATIONS OF SPEECH AND LANGUAGE THERAPY?

There may not be a specialist speech and language therapy service commissioned in your area to work with people with dementia. Taking part in a speech and language therapy intervention can entail a lot of hard work for you and your friends or family.

WHO CAN PROVIDE ME WITH SPEECH AND LANGUAGE THERAPY?

A qualified speech and language therapist or a person working under their direction e.g. a speech and language therapy assistant, friends, or family members.

WHERE CAN I ASK FOR SPEECH AND LANGUAGE THERAPY?

You can ask your GP or local memory service for a referral to speech and language therapy. Some services also allow you to refer yourself. What is provided by services can vary according to area. Therapists in private practice are registered with the Association of Speech and Language Therapists in Independent Practice. They may be contacted on www.helpwithtalking.com.

WHERE CAN I FIND MORE INFORMATION ABOUT SPEECH AND LANGUAGE THERAPY FOR MYSELF?

The Royal College of Speech and Language Therapists (RCSLT) is the UK professional body. Information can be found on their website www.rcslt.org or on this factsheet about dementia:

<https://www.rcslt.org/wp-content/uploads/media/Project/RCSLT/rcslt-what-is-slt-factsheet.pdf>

WHAT IS THE EVIDENCE FOR SPEECH AND LANGUAGE THERAPY?

There is some evidence that speech and language therapy can be beneficial for people with dementia and can help to facilitate communication and involvement in decision-making (Volkmer et al., 2020; Murphy & Oliver, 2013; Hickey & Bourgeois, 2011).

WHO APPROVES/RECOMMENDS SPEECH AND LANGUAGE THERAPY?

Speech and language therapy is recommended by the National Institute of Health and Care Excellence, the Royal College of Psychiatrists and the Royal College of Speech and Language Therapists.

National Institute of Health and Care Excellence (NICE) Guidelines NG97, Standard 1.10.7 (National Institute of Health and Care Excellence, 2018).

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme* (MSNAP) Standards, Standard 32.

Royal College of Speech and Language Therapists (2014). Speech and language therapy provision for people with dementia. Position paper.

Section contributed by Claire Devereux, Specialist Speech and Language Therapist, Mental Health Services for Older People, Sussex Partnership NHS Foundation Trust.

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 behavioural therapy (CBT) is also often used to help people to manage overwhelming feelings of stress and anxiety.

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 wellbeing.

Techniques for relaxation include:

- guided meditation
- yoga
- tai-chi
- applied relaxation
- breathing exercises
- exercise
- activities, e.g. 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 sessions run for a set number of sessions and will usually meet on a weekly basis. You will need to attend all 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 and therefore whilst you may learn how to manage 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 CBT may be more useful to you.

WHO CAN PROVIDE ME WITH STRESS/ANXIETY MANAGEMENT?

Anxiety management groups are run through your memory service. You can join an anxiety management group to learn about different techniques and ways of coping with anxiety. 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 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 MANAGEMENT?

National Institute of Health and Care Excellence (NICE) Guidelines NG97, Standards 1.4.1 and 1.7.11 (National Institute of Health and Care Excellence, 2018).

Royal College of Psychiatrists (2020). *Memory Services National Accreditation Programme (MSNAP) Standards*, Standard 187.

Walking groups

WHAT ARE WALKING GROUPS?

Walking groups are an organised activity group, usually facilitated by a volunteer or peer. However, in theory they can be arranged informally – as long as this is group based. Walking groups are an opportunity for social contact as well as physical activity.

WHO ARE WALKING GROUPS FOR?

Walking groups are for anyone, and as with many groups this is an activity which you can do with your partner, family, and friends. Some groups are organised for specific interests such as people with dogs or nature lovers, and there are often groups geared towards different levels of physical activity. There are also specialist walking groups for parties which include a person using a wheelchair.

WHAT DO WALKING GROUPS INVOLVE?

Walking groups are an organised group which meets regularly to take part in a short walk, typically under an hour, although this can vary. It is an opportunity to engage with nature and the outdoors as well as socialise with other people. The Walking group leader will have prepared a specific route for walkers to follow with the group aiming to complete the walk together.

HOW LONG DO WALKING GROUPS TAKE?

Walking groups typically take under an hour, depending on the route chosen by the group leader, or the specific type of walk chosen. Some facilitators are able to offer a programme of walks which you are able to attend on a casual basis. Regular participation is required in order to benefit from this activity.

WHAT BENEFITS MIGHT I SEE FROM WALKING GROUPS?

Research has found that walking groups have benefits above and beyond helping people to be more physically active. These include:

- it is a form of exercise – health benefits such as weight loss, reduced body fat, reduced blood pressure, improved lung power, improved resting heart rate and reduced cholesterol;
- benefits to mental health, particularly to mood including reduced feelings of depression;
- improve your confidence;
- keeping fit and active can reduce the risk of falls;
- an opportunity to meet and talk with others as well as to chat with others in a similar situation to you;
- as it is a social activity, it can help to maintain motivation to keep physically active;
- it can be enjoyable and interesting!

WHAT ARE THE POSSIBLE LIMITATIONS OF WALKING GROUPS?

Whilst there are no reported side effects of walking groups, there are of course all the risks normally associated with walking such as the possibility of falls. Finding a suitable group in your particular area may also be a barrier to accessing this kind of activity, as it often relies on the efforts of volunteers to operate.

WHO CAN PROVIDE WALKING GROUPS?

Walking groups are often provided by trained lay volunteers rather than health professionals. Group leaders are expected to have a knowledge of the route and the area and be able to guide walkers safely to their destination.

WHERE CAN I ASK FOR ADVICE AND SUPPORT WITH WALKING GROUPS?

Local health and social care services often have information on local walking groups, as keeping active and healthy is a public health priority in the UK. There are large organisations spanning which can be accessed via the internet, the largest network in the UK is Walking for Health.

WHERE CAN I FIND MORE INFORMATION ON WALKING GROUPS?

Walking for Health – <https://walkingforhealth.org.uk/>

Paths for all – information on dementia friendly walks in Scotland – <https://pathsforall.org.uk>

Ramblers, <https://ramblers.org.uk/go-walking>

Meetup, a website for connecting with groups near you, <https://meetup.com>

Rambling Clubs – <https://ramblingclubs.com>

Walks with Wheelchairs – <https://walkswithwheelchairs.com>

Walking in England – details of walks including local walking clubs – <https://www.walkinginengland.co.uk/>

WHAT IS THE EVIDENCE FOR WALKING GROUPS?

As well as strong evidence that walking has wide-ranging benefits for physical health (Hanson & Jones, 2015), walking groups can be a generally accessible physical activity which allows for connection with other people and with nature, and which promotes feelings of agency, ability and inclusion (Robertson et al., 2020; McDuff & Phinney, 2015).

WHO APPROVES/RECOMMENDS WALKING GROUPS?

The National Institute for Health and Care Excellence (NICE) recommends that a range of activities to promote wellbeing are offered, that are tailored to personal preference, in NG97, standard 1.4.1 (National Institute for Health and Care Excellence, 2018).

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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 wellbeing in regards to health and happiness.

Reminisce/Reminiscence

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

Signpost/Signposting

A way of finding out where to obtain more information on a particular topic.

Therapy/Therapist

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

Wellbeing

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.

Speech and language therapist

A healthcare professional trained to assess and treat a person with specific speech, language and communication problems to help them to communicate to the best of their ability. They work directly with people of all ages.

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/Mental health nurse

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

Radiologist

A physician who specialises in radiology, 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.



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