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Non-Cognitive Symptoms of Dementia (NCSD)

Guidance on Non-pharmacological Interventions
for Healthcare and Social Care Practitioners



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If citing this report, please reference it as:

McGowan, B., Gibb, M., Cullen, K., Craig, C. (2019). Non-Cognitive Symptoms of Dementia (NCSD): Guidance on Non-pharmacological Interventions for Healthcare and Social Care Practitioners. Tullamore: National Dementia Office.

Contents

Foreword	4
Funding	5
Acknowledgements	5
Overview	6
Glossary of terms	7
SECTION 1 · BACKGROUND	9
1. Introduction	10
1.1 Scope and intended use of the guidance	10
1.2 Development process	11
2. Non-Cognitive Symptoms of Dementia and their prevalence	12
2.1 Prevalence and natural history of NCSD	14
2.2 A closer look at NCSD	16
SECTION 2 · GUIDANCE	19
3. Introduction	20
4. Prevention as an intervention for NCSD	21
4.1 Person-centred care	22
4.2 Support for family carers	24
4.3 Staff skills and support	25
4.4 Effective communication skills	26
4.5 Environmental adaptation	32

5. Assessment of behavioural change	35
5.1 Framework 1: 'Optimising treatment and care for people with behavioural and psychological symptoms of dementia' (Alzheimer's Society UK, 2011)	35
5.2 Framework 2: RAGSTER	36
5.3 Behavioural analysis tools	40
5.3.1 ABC – Antecedent, Behaviour and Consequence model	40
5.3.2 NDB – Need-driven Dementia-compromised Behaviour model	41
6. Interventions	43
6.1 Selecting interventions	44
6.2 Research evidence	45
6.3 Specific evidence-based interventions	47
> Meaningful activities	48
> Music therapy and other music based interventions	50
> Gardens and garden therapy	52
> Physical exercise	54
> Light therapy	56
> Aromatherapy	58
> Massage and touch therapy	59
> Assistive technology and telecare	60
> Simulated and robotic therapy	62
> Animal assisted interventions	64
> Doll therapy	66
Other therapeutic interventions	68
> Validation therapy	68
> Reality orientation therapy	70
> Reminiscence therapy	71
> Lifestory work	72
> Cognitive Stimulation Therapy	74
> Cognitive Rehabilitation	76
References	78
Appendix	85

FOREWORD

One of the priority actions of the National Dementia Strategy (December 2014) was that the Health Service Executive would “develop guidance material on the appropriate management of medication for people with dementia, and in particular on psychotropic medication management, and make arrangements for this material to be made available in all relevant settings, including nursing homes”. This action was based on emerging international evidence of the risks of psychotropic medications for a person with dementia which indicated a need for careful and considered use of these medications, for a correct indication, and on a trial basis with careful review for efficacy and side-effects.

This action led to the development of National Clinical Guideline No.21 “Appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia”, by a national expert group led by the National Dementia Office, launched by the Department of Health in December 2019. The guideline has an accompanying clinical algorithm, patient information leaflet, and clinical audit tool (all available at <https://dementiapathways.ie/resources-for-practice/non-cognitive-symptoms-of-dementia>).

As this National Clinical Guideline was being developed, it became increasingly apparent that there was an equal need for guidance on non-pharmacological interventions for non-cognitive symptoms, even if not specified as an action in the National Dementia Strategy. The vision of the National Dementia Office was that a companion guidance document would be developed, focusing on non-pharmacological interventions, so as to provide a more holistic approach to the issue of non-cognitive symptoms. The Dementia Services Information and Development Centre (DSIDC) was commissioned by the National Dementia Office to develop this guidance document, given their experience and expertise in this area.

We hope that, taken together, the National Clinical Guideline and this companion guidance document will provide useful guidance for HealthCare and Social Care Practitioners, in any setting, who care for people with dementia. Our vision is that people with dementia are supported wherever possible to make decisions about their own care, in partnership with their doctors, nurses, health and social care professionals and family carers following a holistic assessment of their symptoms and care needs and all relevant circumstances. These care decisions need to reflect current evidence on best practice dementia care such as provided in this guidance document.

We are grateful to the DSIDC and the expert advisory group for developing this guidance document and we hope it is useful to you.

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FUNDING

This guidance document was commissioned by the National Dementia Office using dormant account funding received from the Department of Health.

ACKNOWLEDGEMENTS

This guidance document was prepared with the assistance of a multi-disciplinary expert Advisory Group whose membership is listed below. This group provided important suggestions and guidance on all aspects of the document and we are greatly appreciative of the time and expertise that they gave to this work.

Thank you to the teams at the DSIDC and the NDO for their valuable assistance in preparing this document.

Thank you also to Kevin Cullen of the Work Research Centre for his hard work and invaluable advice in the preparation of this guidance document.

Membership of the Advisory Committee was as follows:

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OVERVIEW

Non-cognitive symptoms of dementia (NCSD) cover a wide spectrum of conditions and situations. At the lower end of the scale they may present as minor eccentricities or be barely noticeable; at the other end of the scale they can be devastating for both the individual concerned and those around them. They are also the most likely reason for placement in a long-term care setting.

There is considerable debate as to what actually constitutes a NCSD. For example, traditionally NCSD have encompassed walking and apathy but there are those who argue that these are in fact core features of dementia rather than symptoms.

It can also be very difficult to determine what behaviour one should be trying to address as most NCSD (apathy apart) co-occur with other symptoms so it is vital that a robust assessment framework is implemented and adhered to.

The question as to whether one needs to actively respond to NCSD also arises. As most NCSD will resolve themselves within a four-week period, sensible approaches, such as the UK Alzheimer Society's concept of 'watchful waiting' is invaluable and a smart counterpoint to the kneejerk 'call the doctor, medication is needed' response.

Through a detailed review of the literature available about NCSD, an examination of existing guidance documents and the assistance of an expert multi-disciplinary advisory committee, this guidance document offers a theoretical grounding in what NCSD are and how they occur, and offers evidence based practical advice for practitioners in a variety of settings.

There is often no quick fix for NCSD and health and social care practitioners must remain flexible and willing to think "outside the box" in their search for answers.

This guidance document is divided into two sections. The first section presents an overview of NCSD and examines the prevalence of specific symptoms and how they often co-occur. It takes a closer look at NCSD symptoms and how their distinctive features make it possible to group them under different domains: behavioural, affective and psychotic.

The second section of the guidance examines practical responses to the emergence of NCSD. It gives primacy to the concept of prevention as an intervention and details five areas of care – person-centredness, the environment, communication, support for family carers, and staff skills and support that could be tackled to minimise or even prevent the emergence of NCSD. It highlights the importance of assessment frameworks for tackling NCSD once they occur and provides two examples of frameworks and behavioural analysis tools that can help staff to explore the NCSD in a structured way. The section concludes with the interventions that are most common in the literature.

GLOSSARY OF TERMS

This section does not contain definitions for the different symptoms that sometimes manifest themselves such as apathy, disinhibition or delusions as these are described in Chapter 2.

Behavioural and Psychological Symptoms of Dementia (BPSD)

The term 'Behavioural and Psychological Symptoms of Dementia' was first used by the International Psychiatric Association (IPA Complete Guides to Behavioural and Psychological Symptoms of Dementia, 1996). These are frequently the expression of unmet needs of the person with dementia. **Behavioural symptoms** include: agitation, restlessness, aggression, walking, shouting and hoarding. **Psychological symptoms** include: anxiety, apathy, depressive symptoms, delusions, hallucinations.

Over recent years there has been a change in terminology from Behavioural and Psychological Symptoms of Dementia to 'Non-Cognitive Symptoms of Dementia (NCSD)' – see definition below. The term Behavioural and Psychological Symptoms of Dementia is used in the document when quoting from text or when detailing a reference.

Dementia

Dementia is not a single condition but rather a term that covers a large number of different conditions, some that will be very familiar to most people, such as Alzheimer's disease and other forms that would be much rarer and therefore not widely known.

The most commonly accepted medical description of dementia is laid out in the American Psychiatric Association's fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). In this edition dementia is termed 'major neurocognitive disorder' although the term dementia is still deemed acceptable. A major change in this edition from earlier descriptions of dementia is the removal of memory impairment as a central criteria for all types of dementia. This recognises that in some conditions the primary presenting symptom may be a speech problem, or a change in personality, depending on the area of the brain that is initially affected. DSM-5 lists six cognitive domains that might be affected in a dementia and there has to be a significant cognitive decline from a previous level of performance in at least one of these domains, resulting in an interference in a person's ability to independently perform their activities of daily living, before a diagnosis of dementia can be made. These domains are:

- › Complex attention
- › Executive function (e.g. planning, decision-making, mental flexibility)
- › Learning and memory
- › Language (including fluency, word finding and the naming of objects)
- › Perceptual motor function (e.g. hand-eye coordination and visual tracking)
- › Social cognition (including recognising emotions and insight)

The National Institute for Clinical Excellence (NICE) in the UK neatly sum up dementia as... *“a term used to describe a range of cognitive and behavioural symptoms that can include memory loss, problems with reasoning and communication and change in personality, and a reduction in a person’s ability to carry out daily activities, such as shopping, washing, dressing and cooking.”* (NICE, 2018)

Non-Cognitive Symptoms of Dementia (NCSD)

Non-cognitive symptoms of dementia (also described as **neuropsychiatric symptoms** of dementia) are common in people with dementia and include symptoms such as: delusions, hallucinations, depression, anxiety, apathy (Dyer et al, 2017; American Psychiatric Association (APA), 2000; Alzheimer Society, 2017). In up to 90% of cases, people with non-cognitive symptoms of dementia may exhibit behaviours that are viewed as challenging such as: wandering; pacing; hoarding; repetitive shouting; inappropriate sexual disinhibition; resisting care etc. (Kales et al, 2019). Using the term NCSD places the emphasis more on the person’s experience (i.e. symptoms) and less on ‘behaviours’ as perceived by others. NCSDs will be discussed in more detail in Chapter 2.

Psychotropic medication

Psychotropic medication is defined as any drug that affects mood and behaviour. These types of drugs cover a number of different categories including anti-depressants, hypnotics and anti-psychotic medications. Prescribing anti-psychotic medications for people with dementia carries with it an ‘increased risk of a number of serious side-effects’. For example, they can lead to ‘a 3-time increased risk of stroke and a 1.7 times risk of all-cause mortality compared with placebo’ (Foley et al, 2019).

Despite the risks of antipsychotics it is still possible that, as a result of the severity of the behaviours or symptoms and in the context of failure of non-pharmacological interventions to reduce distress and manage associated risks, a certain number of people experiencing BPSD/NCSD will require antipsychotics. See “Appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia. National Clinical Guideline No. 21” (Department of Health, 2019; <https://www.gov.ie/en/collection/c9fa9a-national-clinical-guidelines/>) for further information.

Responsive behaviours

“Responsive behaviours is a term, preferred by persons with dementia, representing how their actions, words and gestures are a response, often intentional, that express something important about their personal, social or physical environment” (Alzheimer Society of Ontario).

The term was also coined as an alternative to the term Behavioural and Psychological Symptoms of Dementia. Whilst both terms acknowledge that the brain is undergoing changes that affect thinking, concentration, orientation, memory, mood and behaviour, the term responsive behaviours ascribes *meaning* to behaviour. It views the behaviour as a means of communication and an expression of need or concern on behalf of the person with dementia. In order to fully understand what the person is trying to express one must get to know who the person is, the uniqueness of their life history and how their circumstances and the environment they are experiencing is affecting them.

Section 1

Background

1. INTRODUCTION

NCSD are amongst the most distressing and challenging dimensions of the dementia experience for all those directly affected – people with dementia, their family carers, and formal care services. Evidence suggests that most people with dementia may experience NCSD over the course of their dementia. NCSD may indicate important unmet needs of the person with dementia such as a need for stimulation or pain control and may cause significant distress (and sometimes risk) for themselves their families and/or formal caregivers. If not effectively addressed, NCSD may also increase the likelihood of moving into long-term care and increase overall care costs.

Pharmaceutical approaches to treatment and symptom management in NCSD have limited effectiveness in many circumstances, and often have substantial and harmful side-effects. This document presents guidance for Irish health and social care practitioners on **non-pharmacological** approaches to addressing NCSD. It complements the recently published National Clinical Guideline on the appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia (NCG No. 21), which recommends non-pharmacological interventions as the first line approach in most presentations of NCSD (<https://dementiapathways.ie/resources-for-practice/non-cognitive-symptoms-of-dementia>).

1.1 Scope and intended use of the guidance

The guidance aims to support health and social care practitioners to address the needs of persons with dementia and their carers affected by NCSD. It provides an up-to-date overview of evidence-based approaches and emerging consensus on best practice, and presents guidance on selecting, recommending, and/or deploying non-pharmacological approaches to addressing NCSD. Through this, the guidance aims to help health and social care practitioners navigate this complicated field, and support best practice in situations where NCSD may indicate important unmet needs of the person with dementia and/or cause distress or risk for the person with dementia and/or others around them.

The guidance document targets the broad range of doctors, nurses, health and social care professionals, support staff, and any other practitioners who have roles to play in treatment and ongoing care for those affected by NCSD. They may be working in any relevant setting, including community/primary care, specialist dementia services, home care, residential care, and acute hospitals.

Given the broad target audience, the guidance aims to provide orientation at two levels:

- principles and procedural approaches to apply in addressing NCSD wherever it presents in the health and social care system
- more detailed guidance on specific approaches and interventions that may be helpful for addressing a range of forms of NCSD.

Both levels of guidance are important for all practitioners, whatever their place and role in the care system and care pathways, even if they will draw on this in different ways and to varying levels of detail in their work. Some practitioners will work especially closely with persons with dementia and/or their carers in dealing with NCSD in an ongoing manner in their daily lives. Where possible, the guidance therefore provides sign-posting to other more detailed resources that may support practical implementation of interventions in these contexts. Other sources of guidance may also be useful in providing more detail and focus for specific groups of practitioners. For example, the International Psychogeriatric Association's (IPA) suite of guides on non-pharmacological treatments for BPSD includes separate guidance documents for specialists, nurses, and primary care physicians (IPA 2012).

1.2 Development process

The development process for the guidance involved three stages:

- Collation of an up-to-date, evidence-based compendium of relevant resource material
- Consultation with an expert advisory group
- Preparation of a 'user friendly' guidance document.

Collation of relevant resource material covered a number of areas. This included:

- Background material on the nature, prevalence and impacts of NCSD
- Existing procedural guidance from Ireland and other countries
- Available clinical guidance documents from other countries
- Evidence base on effectiveness of interventions in addressing NCSD and their impacts.

This resource base covered a very broad field, where the volume of published material (both guidance and research evidence) has been growing substantially over recent years. It is also a field where interpretation of the evidence and its translation into practice is not straightforward. This is apparent in the variation across existing guidance documents, particularly in their recommendations on the most effective interventions indicated from the research evidence. It is also manifest in the inconsistent conclusions drawn by different systematic reviews, sometimes even when they substantially overlap in the studies they cover.

A robust but pragmatic approach was applied in the preparation of this first Irish guidance document on non-pharmacological interventions for NCSD. Details of the resource materials drawn-upon are provided in the relevant sections of the guidance.

2. NON-COGNITIVE SYMPTOMS OF DEMENTIA AND THEIR PREVALENCE

This chapter presents an overview of NCSD. It outlines the broad spectrum of NCSD that may present in people with dementia, reviews prevalence data for different symptoms, and looks more closely at the characteristics and impacts of some of the core categories of NCSD.

NCSD covers a wide range of different behaviours and symptoms some of which occur on their own but often occur in clusters. Despite all the research in this area there is no agreed 'official' list of symptoms. A number of different frameworks have been developed to try and map and categorise the range of symptoms and these frameworks can help to support formal and family care provision and the clinical assessment of NCSD. Two of the better-known assessment frameworks are the Neuropsychiatric Inventory (NPI) Questionnaire and the BEHAVE-AD rating scale.

The widely used NPI covers 12 symptom areas over four different domains (Table 2.1 adapted from Cummings et al 1994).

Domains	Symptoms
Psychotic	<ul style="list-style-type: none"> › Delusions › Hallucinations
Hyperactivity (behavioural)	<ul style="list-style-type: none"> › Agitation/Aggression › Disinhibition › Irritability/Lability › Motor behaviour (inappropriate)
Affective	<ul style="list-style-type: none"> › Dysphoria/Depression › Anxiety › Euphoria/Elation › Apathy/Indifference
Modifications in instinctive behaviours	<ul style="list-style-type: none"> › Night-time behaviour › Appetite/Eating

Alternatively, the BEHAVE-AD rating scale (Table 2.2) covers 25 items in seven major categories (Reisberg et al, 1996).

Table 2.2 • BEHAVE-AD Items	
Paranoid and delusional ideation	<ul style="list-style-type: none"> › “People are stealing things” delusion › “One’s house is not one’s home” delusion › “Spouse (or other caregiver) is an imposter” delusion › Delusion of abandonment (e.g. to an institution) › Delusion of infidelity › Other suspiciousness or paranoia › Other delusions
Hallucinations	<ul style="list-style-type: none"> › Visual › Auditory › Olfactory › Haptic › Other
Activity disturbances	<ul style="list-style-type: none"> › Wandering › Purposeless activity (e.g. opening and closing pocketbook, asking same question over and over) › Inappropriate activity (e.g. hiding objects)
Aggressiveness	<ul style="list-style-type: none"> › Verbal outbursts › Physical threats and violence › Agitation (e.g. nonverbal anger, negativity)
Diurnal rhythm disturbances	<ul style="list-style-type: none"> › Day-night disturbances (e.g. repetitive awakenings at night)
Affective disturbances	<ul style="list-style-type: none"> › Tearfulness › Depressed mood (e.g. stating “I wish I were dead”)
Anxieties and phobias	<ul style="list-style-type: none"> › Anxiety about upcoming events › Other anxieties (e.g. regarding money or memory) › Fear of being left alone › Other phobias (e.g. fear of bathing)

Source: Reisberg et al (1996)

2.1 Prevalence and natural history of NCSD

The research suggests that almost all people with dementia will experience some NCSD over the course of the condition. Studies of both nursing home and community populations have found that NCSD are highly prevalent, although there is little consensus on how frequently they occur. Selbaek et al (2013) carried out a systematic review looking at prevalence and the course of neuropsychiatric symptoms (i.e. NCSD) in nursing home patients with dementia and found that agitation was by far the most commonly reported symptom.

Table 2.3 · Prevalence of neuropsychiatric symptoms in nursing home patients with dementia (%)

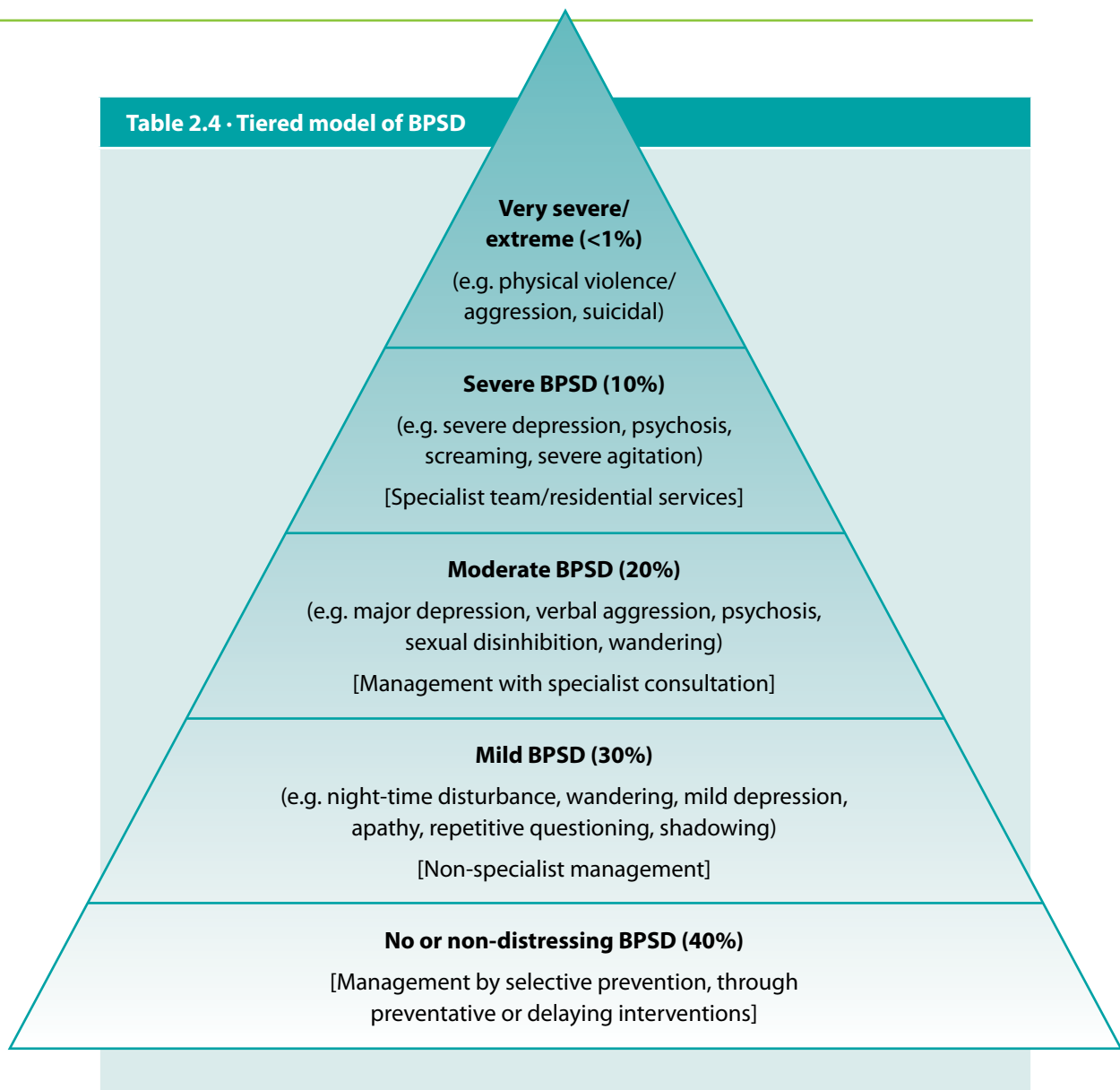
	Any symptoms	82
Behavioural	Agitation (any)	79
	Aggression	32
	Irritability	31
	Disinhibition	18
Psychosis	Delusions	22
	Hallucinations	14
Affective	Affective (any)	28
	Depression	20
	Anxiety	21
	Apathy	36

Source: Selbaek et al (2013)

Other more recent studies (Borsje et al, 2014 and Van der Linde et al, 2016) found that delusions/delusional misidentification, wandering/agitation, aberrant motor behaviour/ motor hyperactivity (e.g. an inability to sit still), and apathy were especially common symptoms.

Van der Linde et al (2016) also found that NCSD such as psychosis, hyperactivity, agitation and physical aggression tend to be associated with greater cognitive impairment.

Finally, Table 2.4 presents a useful perspective on prevalence by showing the approximate distribution of NCSD at different levels of severity across the population of people with dementia. Based on a model developed in Australia, this approach also indicates the level of specialism that may be necessary for management of BPSD at different degrees of severity.



Source: modified version of schema developed by Brodaty et al (2003)

The diagram shows that the majority of NCSD (70%) fall into the mild or non-distressing categories and generally don't require specialist input.

2.2 A closer look at NCS D

The material presented earlier in this document shows that NCS D is an umbrella term for a number of different symptoms. In the research literature these symptoms are sometimes grouped under three different domains – behavioural, affective and psychotic. Although these may sometimes have the same root cause and may also attract similar types of intervention their distinctive features may require that the interventions are tailored in a particular way to have an impact.

Behavioural symptoms

It is now accepted that many of the behavioural symptoms of dementia are best understood and addressed as *responsive* behaviours indicating distress experienced by the person with dementia. These symptoms which include agitation, aggression, irritability and sexual disinhibition may present differently for individuals as they result from a combination of neurodegenerative changes in the brain, personal history, external triggers, and other factors.

In its 'Complete Guide to BPSD' (2012), the International Psychogeriatric Association discuss the mix of psychological factors that may cause or contribute to BPSD. They acknowledge the physiological changes to the brain associated with the dementia but also see a central role for psychological processes that could trigger unusual moods and behaviours.

Possible triggers for these psychological changes include:

- **Unmet needs:** BPSD may originate from or be expressions of unmet universal human needs (such as meaningful activity, emotional validation, and social interaction); without support from caregivers, people with dementia may be unable to voice these needs and/or act to address them.
- **Learnt behaviour:** behaviours may be reinforced if they lead to people experiencing positive outcomes.
- **Stress:** dementia reduces people's capacity to cope with stress, resulting in inappropriate behaviours when levels of stress are excessive.

The IPA guidelines suggest that psychosocial interventions are often based on a blend of all three theories.

The IPA guidelines and others, such as the New South Wales 'Assessment and Management of People with BPSD', present a more detailed breakdown of some of the symptom groups and, in some instances, of the actual behaviours (NSW Ministry of Health 2013). For example, in the New South Wales handbook, sexual disinhibition is broken down into different actions and this differentiated approach highlights the broad variety of behaviours within a symptom grouping and provides insights to possible interventions.

Affective symptoms

Affective symptoms include conditions such as depression, anxiety and apathy. It is also important to be aware that some people exhibiting NCSO may have underlying or related conditions, such as bipolar disorder, and suggest grouping euphoria and disinhibition with the other affective symptoms from this perspective (Dorey et al, 2008).

Both the Selbaeck (2013) and the van der Linde et al (2016) reviews found high prevalence for any affective symptom, as well as specifically for depression, anxiety, and apathy in people with dementia. In practice terms it is important to tease apart apathy from depressive symptoms – either by clinical judgement or by use of a formal screening tool such as the Geriatric Depression Scale (GDS) or the Cornell Depression Scale.

It is quite common for people with dementia to experience depression, although it may be difficult to distinguish against the background of other NCSO. Where it is present in a person with dementia it may contribute to greater disability, caregiver stress and mortality (Meyers, 1998). The relationship between depression and dementia is complex and unclear, with evidence that earlier life depression may be a risk factor and later life depression may be an early symptom of the disease (Bennett and Thomas, 2014). Risk factors for depression in Alzheimer's disease include family history of mood disorders, own previous depressive history, female gender, and younger age of onset of dementia (Mortby et al, 2012). A 2019 cross-sectional study of over seven thousand individuals with Alzheimer's disease, found no interaction between depression and apathy but did find apathy was associated with worse function, especially in the mild dementia range (Zhu et al 2019).

Anxiety is also a fairly common feature of dementia, although it may be difficult to distinguish in dementia because of overlaps with depression and other NCSO (Seignourel et al. 2008). It is associated with lower quality of life and poorer outcomes, even when controlling for depression, and merits attention and possible treatment in its own right. It would be important to obtain a detailed past history of anxiety or treatment for other mental health in order to ascertain whether intervention is warranted.

Psychotic symptoms

Psychotic symptoms include hallucinations and delusions and the research indicates relatively low prevalence rates for hallucinations and moderate rates for delusions. The Selbaeck et al (2013) systematic review in nursing home patients with dementia found the mean prevalence for delusions was 22% and for hallucinations was 14%; for studies using NPI, the means were slightly lower at 19% for delusions and 9% for hallucinations.

Consensus is lacking on whether delusions and hallucinations in dementia should be classified separately or considered part of a broader construct of psychosis in dementia. Evidence suggests they may have separate neuroanatomical bases and that hallucinations may be more indicative of the presence of an overall psychotic syndrome.

Hallucinations are sensory experiences occurring without actual sensory stimulation. In dementia they are most commonly visual, but can involve any of the senses – hearing, somatic, smell or touch. Recurrent visual hallucinations are an

important feature in the diagnosis of some forms of dementia, such as dementia with Lewy bodies and Parkinson's disease dementia.

Delusions are fixed false beliefs and common examples in dementia include delusions of theft, suspicion, abandonment, misidentification, danger, infidelity, and that 'one's house is not one's home', and these may vary in the strength of their reality basis. Some commentators suggest consideration of misidentification as a separate category of symptom.

As well as the accurate diagnosis of a dementia, a detailed past history of mental illness, with attention to lifelong personality traits and evidence from a person's life story will be vital in tailoring individual management plans for all NCSD.

Section 2

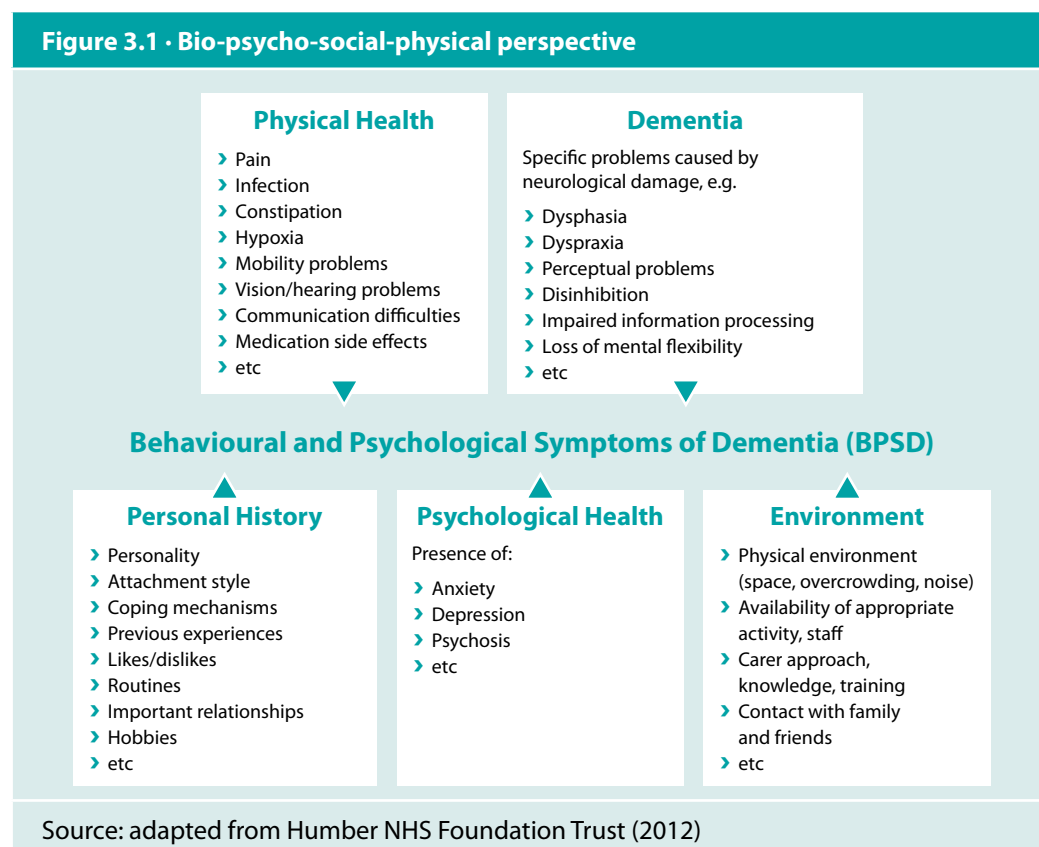
Guidance

3. INTRODUCTION

This chapter presents guidance for healthcare and social care practitioners on how to determine appropriate responses to NCSD. It aims to be helpful for any healthcare professional who has a role in addressing NCSD in their part of the overall health and social care system for people with dementia.

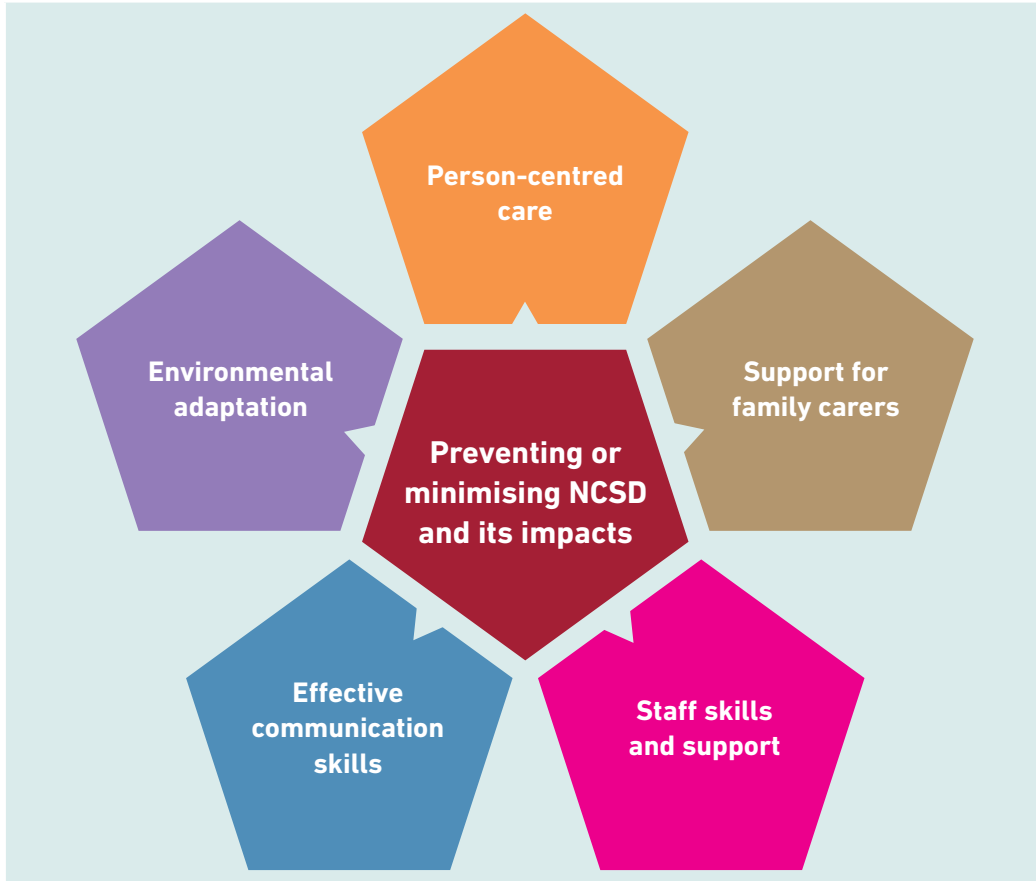
Some practitioners (e.g. GPs, community nurses, and other providers of community and homecare supports) may be the first to notice or be the first port-of-call for family carers when a person with dementia first experiences NCSD. They have important roles in preventative approaches, and in ongoing support in the primary and community care context. Others may have more continuous day-to-day engagement with persons with dementia experiencing NCSD, including family carers and staff in residential healthcare settings.

The guidance follows the biopsychosocial perspective on how to help understand and address NCSD (Figure 3.1). This recognises the influence and interplay between biological (neurodegenerative), psychological, and social factors in the aetiology and/or triggering of NCSD. Some commentators suggest a broadening of the concept to ‘bio-psycho-social-physical’ to ensure that aspects such as the physical environment, physical health and physical care are also kept to the fore (Keady et al, 2012).



4. PREVENTION AS AN INTERVENTION FOR NCSD

Figure 4.1 · Key foundations of a preventative approach



The old adage ‘prevention is better than cure’ was never more true than when discussing non-cognitive symptoms of dementia. Certain issues can be addressed, such as person-centred care, support for both formal and family caregivers, effective communication skills and environmental adaptations, that will minimise the risk of NCSD occurring. If and when NCSD do occur then having these factors addressed is likely to give any subsequent interventions a better chance of success.

In the following section, each of these factors, which need to be regarded as interventions in their own right – person-centred care, support for both formal and family caregivers, effective communication skills, and environmental adaptations, are examined in more detail.


 Person-centred
care

4.1 Person-centred care

The concept of person-centred care remains at the heart of all good dementia care practice. But what exactly is it and what is the thinking behind the words?

Person-centred care (PCC) is a philosophy of care which focuses on the needs of the individual and requires having knowledge of, and interpersonal interaction with, the individual as a 'person'. It is a way of delivering care in which the individual person and their preferences are prioritised, instead of the disease, its expected symptoms and challenges, and the reduced abilities of the person. Person-centred care recognises that dementia is only a diagnosis of a condition affecting the person, and that there is much more to the person than their diagnosis.

The PCC approach recognises that unmet needs may be the basis of NCSD in people with dementia and encourages health care providers to understand and provide the necessary supports for these unmet needs. PCC also emphasises that caregivers should recognise the person with dementia as having personal beliefs, abilities, a life story and experiences, along with relationships that are important to them and contribute to who they are as a person. On a day-to-day basis, PCC attempts to view the world through the eyes of the person with dementia.

In residential care settings and homecare PCC requires a fundamental shift in thinking away from the more traditional task-oriented approach that focuses on schedules and on staff and organisational needs. To be successful it requires commitment from everyone within the organisation, from management to frontline staff. Despite sometimes being referred to as "person-directed," "resident-focused" or something similar, the core principles are essentially the same (Fazio et al 2018, Chenoweth et al 2019). Kitwood's seminal work (Kitwood 2007) in this area developed some PCC principles to assist health and social care professionals and family carers support the person's well-being, which include:

- creating and strengthening a positive relationship with the person through warm and accepting human contact;
- communicating respectfully, valuing and honouring the person;
- treating the person as a sentient and unique human being by valuing their innate nature;
- assisting the person to retain their remaining strengths; viewing the person's world from their own perspective;
- enabling the person to feel socially confident and maintain emotional attachments.

Multiple sources, including international policy, dementia advocacy groups and national Dementia Strategies, including the Irish National Dementia Strategy (2014), advocate PCC for people living with dementia. In the UK, the National Institute of Clinical Excellence (NICE) guidelines on *Dementia: assessment, management and*

support for people living with dementia and their carers emphasise that the philosophy of person-centred care is fundamental to good practice in dementia care, and this is reflected in the recommendations (NICE, 2018).

PCC also has a growing evidence base of effectiveness. A systematic review and meta-analysis found evidence that PCC can reduce agitation, other neuropsychiatric symptoms, and depression and improve the quality of life of people with dementia (Kim and Park, 2017). For agitation, short-term activity-based and individualised interventions had a greater effect than long-term interventions. Larger and more sustainable effects on improving quality of life were found for staff education and cultural change interventions. A separate systematic review also found evidence for effectiveness of person-centred care approaches at the organisational-level to support the quality of life of people living with dementia (Chenoweth et al 2019). Table 4.1 presents a summary of practice recommendations for person-centred care.

**Table 4.1 · Practice recommendations for person-centred care
(adapted from Fazio et al 2018)**

- 1. Know the person living with dementia.** Recognise that the person living with dementia is more than a diagnosis. It is important to know the unique and complete person, including his/her values, beliefs, interests, abilities, likes and dislikes – both past and present. This information should inform every interaction and experience.
- 2. Recognise and accept the person’s reality.** It is important to see the world from the perspective of the person living with dementia as this will help to recognise behaviour as a form of communication thereby promoting effective and empathetic communication that validates feelings and connects with the individual in his/her reality.
- 3. Identify and support ongoing opportunities for meaningful engagement.** Every experience and interaction can be seen as an opportunity for engagement. Engagement should be meaningful to, and purposeful for, the individual living with dementia. It should support interests and preferences, allow for choice and success, and recognise that even when the dementia is most severe, the person can experience joy, comfort, and meaning in life.
- 4. Build and nurture authentic, caring relationships.** Persons living with dementia should be part of relationships that treat them with dignity and respect, and where their individuality is always supported. This type of caring relationship is about being present and concentrating on the interaction, rather than the task. It is about “doing with” rather than “doing for,” as part of a supportive and mutually beneficial relationship.
- 5. Create and maintain a supportive community for individuals, families, and staff.** A supportive community allows for comfort and creates opportunities for success. It is a community that values each person and respects individual differences, celebrates accomplishments and occasions, and provides access to and opportunities for autonomy, engagement, and shared experiences.
- 6. Evaluate care practices regularly and make appropriate changes.** Several tools are available to assess person-centred care practices for people living with dementia. It is important to regularly evaluate practices and models, share findings, and make changes to interactions, programs, and practices as needed.

4.2 Support for family carers

Family carers are often central in the provision of care for people with dementia living in the community. They need support to develop skills to fulfil this role, as well as supports to address their own needs arising from the pressures and challenges of caring for a person with dementia. The requirement for both forms of support may be especially great when NCSD are causing significant challenges and distress.

In the UK, the NICE guidance on dementia care gives substantial attention to this aspect. Support requires tailoring to their personal circumstances and needs as well as those of the person with dementia they are caring for. Relevant elements of the NICE recommendations include:

- Consider offering carers and/or family members the opportunity to attend and participate in dementia specific training sessions; group sessions may be especially effective
- Relevant topics include: understanding dementia; developing personalised strategies and other carer skills; addressing and coping with challenging behaviours; how to plan and carry out meaningful activities with the person with dementia; communication skills; and how to look after their own health and wellbeing
- Advise carers on their rights and the services available to them (e.g. respite)
- Be aware of the increased risk of depression amongst carers of people with dementia (and address or refer as appropriate).

The important area of communications skills is covered in more detail later in this section, and is relevant for family carers as well as care staff and all healthcare and social care practitioners.

In Ireland, the importance of providing family caregivers with the necessary tools and information has also been long recognised by the organisations working in this field. In a recent HSE National Dementia Office commissioned guidance that draws upon international research and best practice, health and social care professionals are advised on how to provide essential information and advice to family caregivers. ('The Next Steps: Dementia post-diagnostic support guidance', DSIDC/NDO, 2019)

4.3 Staff skills and support

Based on the available evidence that interventions to train staff in person-centred care produced improvements in both agitation and quality of life for people with dementia, the NICE guidelines provide a number of recommendations in this area. In the absence of clear evidence in favour of any individual training programme being more effective than another, the recommendations highlight the key elements of the interventions, rather than being prescriptive on exactly how an intervention should be structured or delivered. Some key elements of the NICE recommendations include:

- Care and support organisations should provide all staff with training in person-centred care and outcome-focused care for people living with dementia
- Relevant topics include: understanding dementia; understanding the person as an individual, and their life story; respecting the individual's identity, sexuality and culture; understanding the needs of the person and their family or carers; principles of the relevant legislation (and regulations)
- Follow-up training and workshops for staff providing care and support for people with dementia on an ongoing basis; relevant elements include:
 - Understanding the organisations' model of dementia care.
 - How to monitor and respond to the lived experience of people living with dementia, including learning different communication skills and techniques.
 - Initial training on understanding, reacting to and supporting people living with dementia who experience agitation, aggression, pain, or other behaviours that challenge indicating distress and unmet needs.
 - Follow-up sessions where staff can receive additional training and discuss and work on examples of situations of behaviours that they may find difficult.
 - Education and training on specific non-pharmacological interventions that have been shown to reduce the need for antipsychotic and other medications used in the management of NCSD.
 - If relevant to staff, the specific needs of younger people living with dementia.

The NICE recommendations also address a number of other areas, including giving carers and/or family members the opportunity to attend staff training sessions and how to engage with family members and carers more generally (e.g. around rights to access information about the person's care). In the Irish context the most recent guidance on dementia care for designated centres for older people was published by HIQA in 2017 (HIQA 2017).



Effective communication skills

4.4 Effective communication skills

For a person living with dementia the gradual loss of their ability to communicate can be one of the most frustrating and challenging problems related to their illness.

Furthermore, as the disease progresses their ability to express their needs, wishes and desires and also to understand what is being said to them becomes increasingly compromised.

For families and healthcare professionals it can be a real challenge to understand what the person living with dementia is feeling, needing and saying, resulting in uncomfortable feelings of inadequacy in understanding and responding to the person's efforts to communicate.

There is generally a combination of reasons that cause this gradual deterioration in the ability to communicate for people with dementia including:

- progression of the neurological disease
- physical and sensory issues
- environmental factors
- and the failure of others in contact with the person to compensate for their impairments or to facilitate use of their retained abilities.

The ability to communicate effectively with the person with dementia is an essential skill that healthcare professionals need to acquire in order to support the person with dementia to express their needs and wishes. (*The National Dementia Strategy, HIQA Standards, ASI Charter of Rights for people living with dementia, Assisted Decision-Making (Capacity) Act, Eggenberger 2013*).

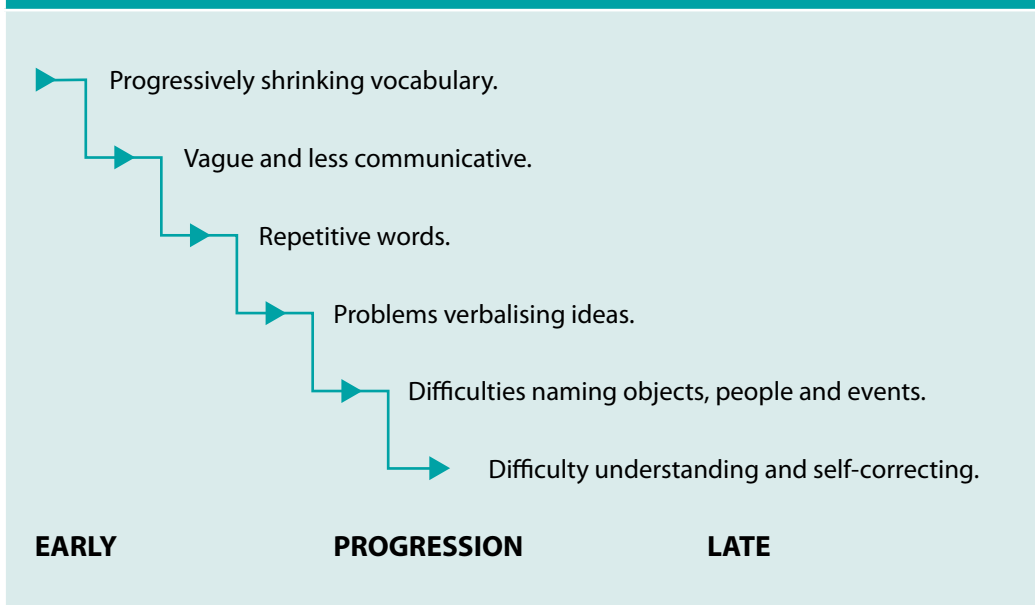
Changes in a person's ability to communicate can have a profound effect on those around them especially for families and those providing care and support. For families and caregivers, relationships can become strained as the ability to talk through problems or offer mutual support becomes more difficult.

Other difficulties such as repetitive questioning or story telling may emerge adding to the strain on the relationship. Finding effective support systems for these groups is essential in order to continue to provide quality care.

Communication remains possible at all stages of dementia and the responsibility of ensuring communication is possible rests with us.

What a person says or does and how a person behaves has meaning, however their ability to communicate with us in the way we always understood with ease is now compromised due to the disease process.

Staff need to be creative and open to trying different approaches to interact, connect with and support the person living with dementia to communicate (Irish Hospice Foundation, 2015).

Figure 4.2 • Communication changes with dementia

What influences communication?

Communication should be viewed as a two-way system. Your communication style and how you communicate with the people you support is affected by a number of factors:

- › **Attitudes and behaviours:** How we are feeling ourselves and our attitude towards our work and people with dementia will have an impact on how we communicate. It is important therefore that we have a high level of self-awareness as we have an important role to play as communication partners.
- › **Environment:** We need to be conscious of the environment we are trying to communicate in – factors such as activity levels, noise, light etc. all impact on communication.
- › **Stressors:** We need to be aware of our own stressors and how we are on a given day. Be aware of how other staff members on the team are and support each other in the context of your work.

The impact of communication difficulties for people with dementia

- › People with dementia who have communication difficulties may become isolated, neglected and excluded from social activities, consequently their needs, abilities and strengths are not acknowledged and supported.
- › This leads to a sense of helplessness and disempowerment.
- › As a result, the person with dementia may not want to engage which brings on more disengagement with the caregiver, creating a vicious circle.

Table 4.2 · Communication techniques for people with dementia**1. Setting up a suitable environment**

Activity Levels – The person with dementia can be over-stimulated in an environment that is “too busy,” e.g. too many people talking at the same time, radio or television playing.

Light – good lighting can help people to see you, what is around them, to navigate, identify signs and spaces.

Noise – reduce background noises such as TV, music, radio, banging, chatting as it can make it very difficult for a person with dementia to concentrate and communicate

Position – where the person is seated will affect how they can interact – can they see and hear ok? Stay still while you are talking, the more the person can focus on you the better.

Aids – do they have their glasses and /or hearing aids in and are they clean and working correctly? Are they comfortable? Do they have whichever communication supports they need e.g. a pen and paper or other supports to hand? Are their communication resources available e.g. visual menus, visual schedules or diaries, calendars, photos, life story book to support communication available?

2. A caring approach

People with dementia are very sensitive to how we look, act, the tone of our voice, our body position and the manner in which we present ourselves will have an impact on our relationship with the person that we are supporting. A friendly, calm, relaxed approach will put the person with dementia at ease even if they do not understand what we are saying.

The caring approach includes the following recommendations:

Address the person by their preferred name, avoid using terms like “love”, “dear”,

Introduce yourself and tell them why you are there.

Do not expect the person to remember you or quiz them, this can be distressing.

Be attentive to the person’s nonverbal communication – use your observations of the person to open up a conversation and if you see a particular emotion, validate/ label it (e.g. I see you are sad/ happy today)

Avoid extremes – talking too loudly or quietly and be aware of your nonverbal communication.

Be flexible and do not argue, remain calm, ask for help if you are frustrated, be patient.

Listen carefully and do not interrupt ensuring that you make communication two way.

Encourage humour and laughter and respect sadness.

3. Body language

Be mindful of the body language YOU present. You may be saying one thing, but your body language may be suggesting another.

Ensure that the person with dementia realises that you are there and SMILE.

Position yourself at their level so that they don't have to look up at you. (Don't stand over the person!)

Use hand gestures and other visual cues to communicate.

Provide touch and contact if they are receptive to this and if it is appropriate.

Be aware of the personal space of the person you are caring for. They may not be comfortable with you in their "whisper zone."

Try to avoid body language that conveys that you are frustrated, angry or in a hurry (even if you are!).

4. Talking clearly

People with dementia have difficulty in remembering and interpreting information, and as dementia progresses, the person's ability to manage complex information declines.

To ensure that communication is successful, the message that you send needs to be short and simple.

Use simple, short sentences and speak at an appropriate volume.

Give one direction/piece of information at a time and give enough time for the person with dementia to process information (10–20 seconds minimum).

Speak slowly and clearly, gauge your pace by the reaction of the person with dementia.

Use words that the person with dementia understands, knows or is familiar with.

Table 4.3 · Using the appropriate words

<i>Talk to the person as an adult!</i>	Use visual supports/ gesture or writing down key words to support the interaction	If the person appears to not understand what you are saying, repeat or rephrase what you have said.
Use close ended questions when trying to do tasks and use open ended questions when you want to open up conversation.	Provide support where a person gets stuck – e.g. you were telling me about..... and how you felt about your day today	Minimise the use of questions. Reasoning, accessing factual memory, logic and time may all be areas which are difficult for a person with dementia.
Provide help in a tactful way and focus on the interaction rather than the facts about the interaction. Correcting the person with dementia is not helpful.	Talk a lot about the past – these memories are much easier for people with dementia to access – you can use a newspaper/photos or anything to start these conversations	Choice based questions (e.g. do you want beef or chicken?) may place extra demands on the person's memory. Think about asking short simple yes/ no questions as these are shown to be more effective for people with advanced dementia
Avoid literal phrases (i.e. It's raining cats and dogs.) which may confuse the person with dementia and avoid using modern slang or jargon	Use visual cues and pictures if you are struggling to get a message across.	Tell the person a bit about yourself Use humour!
Use words that are positive, encouraging and reassuring.	Watch for signs of frustration.	<i>Don't pretend you have understood if you don't!</i>

Key messages

Communication difficulties are common in dementia and can be expressive and/or receptive. They are linked to reduced quality of life and reduced quality of care.

- › All behaviour must be viewed as a form of communication, often non-verbal
- › Enter their reality – cross the bridge to connect successfully
- › Communication is possible throughout the journey of dementia
- › Frameworks, strategies and therapies are available to aid communication
- › Listen to the music and not the words – the emotions and feelings are real
- › The responsibility for successful communication/interaction rests with us

Useful links

- › https://alzheimer.ie/wp-content/uploads/2018/11/Communication_Section-B2_website.pdf
- › <https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms/tips-for-communicating-dementia>
- › <https://www.alz.org/help-support/caregiving/daily-care/communications>
- › https://www.dementia.org.au/sites/default/files/20090901-NATSIDAG-FacilitatorsGuide_Sec-11_Ways_of_Communicating.pdf
- › <https://alzheimer.ca/en/Home/Living-with-dementia/Ways-to-communicate>
- › <https://www.understandtogether.ie/Get-involved/Individual/Tips%20on%20how%20to%20communicate%20with%20a%20person%20with%20dementia.pdf>

4.5 Environmental adaptation

Another key factor in responding to NCSD is to give careful consideration to the physical environment that the person with dementia is operating in. Put simply complex environments will cause us all some difficulty and this is especially the case for someone with a dementia. As the condition progresses it can make it more difficult for a person to: make sense of their surroundings; find their way around and; understand how things work.

Over the past 30 years there has been a growing interest in the field of environmental design and dementia and this is reflected in the burgeoning amount of research accruing on the subject. Despite all of this research, hard evidence is difficult to come by and it remains the case that, to some extent, we are still working from the basis of generally agreed professional consensus. This consensus has tended to coalesce around a number of core issues and this is reflected in a Norwegian study (Landmark et al, 2009) that examined the findings of eight systematic reviews and 11 primary studies on the impact of the design of the environment on people with dementia. They summarised their findings thus:

- › That smaller, less crowded environments led to less NCSD
- › That people found it easier to orientate themselves in smaller environments
- › Crowding, noise and high stimulus in bathrooms, corridors and elevators led to increased agitation
- › That increased lighting led to improved orientation and reduced behavioural disturbance
- › That single rooms that were homelike and personalised led to reduced psychiatric symptoms
- › Toilets that were easy to find and use were used more frequently

This all sounds relatively straightforward to achieve and, for those people with dementia who are living at home or in the home of a relative, this may very well be the case. However, for those people with dementia who are living in another type of care setting, achieving what appear to be comparatively modest goals may prove far more complicated and costly for the managers and owners of the institutions.

How, and to what extent, a nursing home or hospital for example chooses to adapt their environments will depend on the resources available and their knowledge and understanding of the topic and of the benefits that it can bring both to the person with dementia and members of staff.

Addressing the size of the environment can bring benefits. Despite mixed research evidence most findings suggests that smaller sized units are associated with better outcomes for people with dementia. These include: “slower decline in ADL skills, more sustained interest in the environment, less aggressiveness, less anxiety, less depression, less use of psychotropic medication and a higher level of community” (Fleming, 2010).

Reducing the size of an environment need not involve extensive rebuilding work. It may just require the strategic positioning of room dividers and a careful reworking of existing space.

Homelike environments have been associated with lower levels of overall aggression, improved quality of life and reduced anxiety (Zeisel et al, 2003; Reimer and Slaughter et al, 2004) and this can be achieved with some good advice on interior design and a move away from the white equals clean and clinical dogma.

The control of external stimuli such as light and noise can help reduce verbal aggression, confusion, anxiety and aggression (Zeisel et al 2003) and improved lighting levels are associated with fall reduction (NICE, 2013) and can enhance people’s ability to perform tasks successfully.

Conditions such as Alzheimer’s disease are associated with symptoms such as confusion and becoming disorientated in unfamiliar environments. A well thought out wayfinding system involving multiple cues and signs can help people in their navigation efforts and help reduce stress and anxiety. Employing techniques such as the progressive disclosure of information, improving visual access, memorable landmarks at decision-making points and signage that include pictorial representation as well as words can all help people with finding their way successfully.

Recommended design guidelines:

- The Building for Everyone (BfE) Booklet series (CEUD, 2014)
<http://universaldesign.ie/Built-Environment/Building-for-Everyone/>
- Trust Housing Association, Housing Design Guides: Remodelling our Existing Housing for the +65s
https://www.trustha.org.uk/media/uploads/documents/03_Remodelling_15_11_XMa7PT8.pdf
- Dementia Friendly Dwellings for People with Dementia, their Families and Carers (CEUD, 2015)
<http://universaldesign.ie/Built-Environment/Housing/Dementia-Friendly-Dwellings/>
- Dementia Friendly hospitals from a Universal Design Approach, Design Guidelines (Trinity Haus, 2018)
<http://dementia.ie/images/uploads/site-images/UD-DFH-Guidelines-2018-Full-doc-lw-res-compressed-A1.pdf>
- Health Building Note 08-02, Dementia-friendly Health and Social Environments (Dept of Health, UK, 2015)
<https://www.gov.uk/government/publications/dementia-friendly-health-and-social-care-environments-hbn-08-02>
- Improving the patient experience. Developing supportive design for people with dementia. The King's Fund's Enhancing the Healing Environment Programme 2009–2012 (Waller et al, 2013)
https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/developing-supportive-design-for-people-with-dementia-kingsfund-jan13_0.pdf
- Good Practice in Design for Dementia and Sight Loss (DSDC, no date)
https://dementia.stir.ac.uk/system/files/filedepot/12/good_practice_in_the_design_of_homes_and_living_spaces_for_people_living_with_dementia_and_sight_loss_final.pdf

5. ASSESSMENT OF BEHAVIOURAL CHANGE

Where preventative approaches are unsuccessful and NCSD becomes sufficiently distressing or problematic to warrant more direct intervention the accepted best practice in dementia care now requires that every effort is made to address NCSD through non-pharmacological approaches before considering the possible use of medications.

Some guidelines make a distinction between emergent and non-emergent NCSD (NaRCAD, 2013). Emergent NCSD is where the person is in severe distress, poses imminent danger to themselves or others, or has severely disruptive or dangerous behavioural disturbances. Pharmacological interventions may need consideration in some such cases; otherwise, non-pharmacological approaches are the recommended first line approach.

In this section, two frameworks that provide the outlines for identifying, intervening and evaluating are discussed. Both are tried and tested in real life settings and have shown to provide a useful guideline for staff and caregivers.

5.1 Framework 1: 'Optimising treatment and care for people with behavioural and psychological symptoms of dementia: a best practice guide for health and social care professionals' (Alzheimer's Society UK, 2011)

This guide aims to help the staff in everyday clinical settings find simple and practical solutions. It uses a colour-coded traffic light system that represents: no symptoms – green; mild or moderate symptoms – amber and; severe symptoms – red.

The green traffic light interventions are based around prevention and involve the monitoring of physical and mental health i.e. checking for depression, pain, delirium and other risk factors as well as ensuring that the tenets of person-centred care are being adhered to and that the person's physical environment is optimised to their needs.

The amber traffic light is designed for responding to mild to moderate symptoms. The concept of 'watchful waiting' – 'an active process over four weeks involving ongoing assessment of contributing factors and simple non-drug treatments' (Alzheimer's Society UK) is introduced. Watchful waiting acknowledges the fact that most NCSD will resolve themselves after four weeks without any pharmacological interventions.

The red traffic light is for those experiencing more severe and stubborn symptoms that will require specific interventions. A full medical and mental health review is called for at this stage as well as consultations with family members or carers for advice on the best way forward. Specific psychosocial interventions designed for the individual using approaches such as the ABC model are recommended, as is further staff training if necessary. The Alzheimer's Society UK guidance also recommends three 'brief and simple' approaches that have proven to be effective in these circumstances. These are: a) improving social interaction by engaging the person on a one-to-one basis for between 10 and 30 minutes each day; b) encouraging exercise and positive activities and; c) undertaking personalised activities such as reminiscing, puzzles and games, or going for a walk. Pharmacological treatments are also dealt with at the red traffic light level, primarily analgesics, antidepressants and antipsychotics, except in the case of those people with a diagnosis of Lewy Body Dementia.

This guidance document comes in a toolkit format, that can be downloaded from the Alzheimer UK website, complete with algorithms and blank forms that can be completed by staff as they work through the severity of the NCSD. This may prove useful to GPs for example, where they could print off and hand out blank forms to family caregivers to help them in the identification of certain behaviours and thus indicating relevant interventions.

You can download the toolkit here: <https://www.alzheimers.org.uk/sites/default/files/2018-08/Optimising%20treatment%20and%20care%20-%20best%20practice%20guide.pdf?downloadID=609>

5.2 Framework 2: RAGSTER

The mnemonic **RAGSTER**, developed in Ireland, is now being widely used in residential nursing centres around the country. It recognises that addressing a person's individual needs demands a comprehensive approach that requires an examination of not only the current situation and environment but also the individual's past experiences, personality and usual routines. Additionally, it is essential that we try to see the world from their perspective and developing from that informed view, ways of responding to their needs. Unique, individualised responses support and meet the individual's needs and are therefore likely to work.

Given that the approach needs to be comprehensive and individualised, it is useful to have a step-by-step guide to help manage the process that can often accumulate much information. A clear view of both the direction and progress when addressing the individual's needs is essential. To this end the mnemonic **RAGSTER** can be helpful. It's easy to remember and use and represents the common elements of any problem-solving approach.

R = Rule out delirium, pain and depression

Changes in behaviours can occur if the individual develops delirium, depression or experiences pain. So, as a first step, it is important for the team to exclude these as possible causes or triggers of the behaviour.

Delirium is a medical emergency and a potentially life-threatening condition. Even though in contrast to dementia its presentation is acute in onset, the clinical features of delirium are similar to dementia and consequently it has been under diagnosed in many settings (*Ryan et al., 2013*). Timely treatment of the underlying causes or triggers is essential to prevent any deterioration. There are a number of validated delirium screening tools, such as:

- **4AT** (MacLulich et al., 2019)
<https://www.the4at.com>
- **CAM** (Confusion Assessment Method, Morandi, 2012)
http://www.hospitalelderlifeprogram.org/uploads/disclaimers/Short_CAM_Training_Manual_8-29-14.pdf
https://www.hospitalelderlifeprogram.org/uploads/disclaimers/Long_CAM_Training_Manual_10-9-14.pdf
- **RADAR** (Recognise Acute Delirium As part of your Routine)
http://www.radar.fsi.ulaval.ca/documents/Formulaire_RADAR_en_2014-Autv4.pdf

Pain also frequently goes undiagnosed and under-treated (*Ferrell 1995, Morrison et al 2000,*) in individuals with dementia but it can be difficult to assess. There are a number of pain assessment tools used particularly for people with dementia. The **Abbey Pain Scale** and **PAIN-AD** are two commonly used and validated tools which are simple and quick to use. A positive result will then be followed by investigation of the pain source and appropriate pain killers.

Depression and dementia are both common conditions in older people and frequently found together. As depression develops, behaviour can change and recognition of this is important. The **Cornell Scale for Depression in Dementia** is a screening tool designed specifically for people with dementia using both observation and informant-based questions. It alerts the team to the possible presence of depression thereby instigating further investigations and consultations with the appropriate expertise.

- **Abbey Pain Scale**
<http://www.wales.nhs.uk/sitesplus/documents/862/FOI-286f-13.pdf>
- **PAIN-AD**
http://dementiopathways.ie/_filecache/04a/ddd/98-painad.pdf
- **Cornell Scale for Depression in Dementia**
<http://www.scalesandmeasures.net/files/files/The%20Cornell%20Scale%20for%20Depression%20in%20Dementia.pdf>

A = Agree and decide on which behaviours to target

These behaviours can vary. They can also occur on their own, in clusters, at different times of the day or fluctuate in intensity etc. To gain an understanding of what is happening to the individual the team needs to explore the various characteristics of the behaviour and agree on which ones to target.

G = Gather information

By far the most important element of this stepped approach is the gathering of information from numerous sources. The individual's life experiences, personality characteristics, the environment, their current physical and psychosocial needs, the context etc. all must be explored to find reasons, answers or triggers for the behaviour. This may produce abundant amount of information which can become overwhelming and difficult to analyse. Frameworks can help in the task of organising all the pertinent information and to make sure nothing is missed. There are a number of these available e.g. the Need-Driven Dementia-Compromised Behaviour model (Kovach 2005) and the Antecedent, Behaviour and Consequence (ABC) tool. All assist in collecting relevant information. This is an important step as it provides the team with a wide range of sources to help identify possible triggers, reasons and causes.

S = Select interventions/solutions

Having recognised some possible triggers or causes from the information gathered, the team then identifies interventions or solutions to implement. These can be divided into three types.

- 1. Standardised interventions or solutions:** these are supported by research and have been shown to work with particular types of behaviour. For example, it is not always possible to recognise unmet needs in a person with dementia. Unmet physical needs tend to be easier to detect but the origin of some, unmet psychosocial needs may go back many years. Using standardised interventions that work for particular behaviours is the option here.
- 2. Elimination of triggers:** having carried out a behavioural analysis using the ABC tool, the team may identify a trigger or triggers. Removal of these triggers will be planned.
- 3. Individualised interventions:** if no triggers have been identified or no standardised solutions are available the team can then design individualised interventions or solutions with the person's unique characteristics in mind. The person's life experiences and stories are used as a resource by the team. These interventions or solutions are sometimes unusual and require the team to think outside the box.

T = Trial of interventions or solutions

A timeline is planned and agreed by the team and communicated to others as necessary. The team intervenes and records. The team meets any unmet needs, removes any triggers and/or develops individualised interventions/solutions. It is important that the gathering and recording of information (using the ABC or NDB models, for example) is an ongoing process throughout the trial period as this will help with the following stages.

E = Evaluate

A timely evaluation of the solutions and interventions is made, distinguishing between what has helped and what hasn't, thereby providing a direction for the future. Questions are asked such as – has the behaviour changed in any way? Has it been eliminated or changed? Has it decreased in frequency or intensity? The answers determine the next step: continue with the interventions and solutions or augment them in some way and initiate others. Keep in mind that the majority of NCSD are time limited and a team-based approach with multi-professional input would be recommended as best practice.

R = Review

The whole **RAGSTER** process is reviewed by the team in relation to its usefulness in supporting the person with dementia through their difficult time.

If the RAGSTER process has not been successful after the first attempt then it should be tried again and it may take several attempts to identify the appropriate interventions/solutions to any given NCSD.

5.3 Behavioural analysis tools

Both the Alzheimer UK and RAGSTER frameworks rely on additional tools to assist in the gathering and assessment of information. There are a number of these tools available and two are highlighted here.

5.3.1 ABC – Antecedent, Behaviour and Consequence model

The ABC tool is based on the premise that some responsive behaviours may occur as a result of factors in the environment that may either trigger or reinforce the behaviour. It is a simple observational tool used by health care workers to record and examine the behaviour and its relationship with environmental events that occur around it. It is expected that any member of staff who is in proximity to the person is able to record specific events or behaviours.

The available ABC tools all record information in a similar manner. For example, each will have the three columns – A = Antecedents; B = Behaviour and C = Consequences in common.

Date	Time	A = Antecedents	B = Behaviour	C = Consequences	Sig

The behaviour to be monitored should be agreed by the team and described for clarity. All staff should be aware which behaviour is being selected and as far as possible record it each time it occurs. However, it is unlikely that every time it occurs it will be observed. A number of recordings of the target behaviour should be made over an adequate period of time to create a 'picture' of the circumstances that surround the incident. This increases the chance to identify any triggers or factors that may reinforce the behaviour(s).

Staff completing the form should start with column B (Behaviour) as this helps to keep the focus on the particular behaviour. The behaviour description should provide a clear picture of the target behaviour.

Column A (Antecedents) is for recording information about what happened just before the behaviour occurred. Examples could include the noise level, interactions, smells of meals being served, a visit of a relative, quietness etc. It is important to enter everything that happened even though it might not appear to be a trigger. Triggers are often identified where they were not suspected.

Column C (Consequences) is used to describe what happened after the behaviour or as a consequence of the behaviour. This might include such things as how upset the person was; other people’s reactions; who spoke to the person; what attention was given etc. The only purpose of this column is to help identify anything that re-enforces the behaviour, thereby perpetuating it.

When there is an adequate number of entries, the chart is analysed. Initially, Column A is examined for each event entry and common factors are looked for. These may be triggers for the behaviour. Where triggers do exist, they are generally found in most events.

If no triggers are identified then column C is examined for factors that might be reinforcing the behaviour(s). These factors are not that common, however, and can be associated with learnt behaviour where people experience positive outcomes for certain actions.

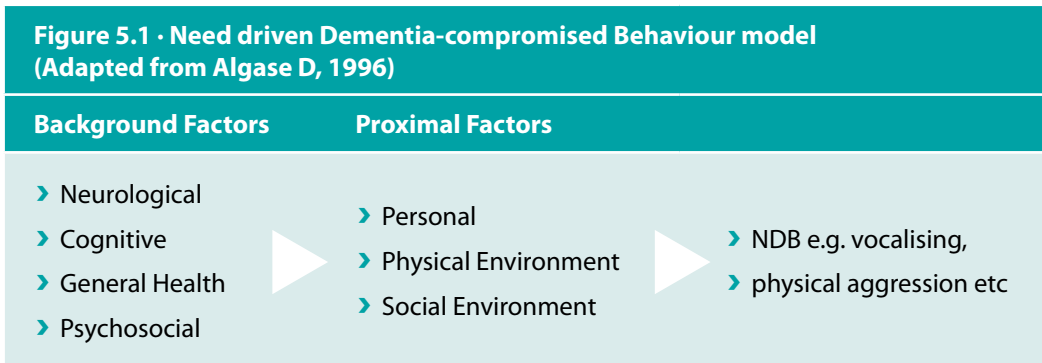
The ABC chart is a simple and useful tool for the recording and identification of circumstances that may trigger and/or reinforce certain behaviours. On its own it is unlikely to provide all the answers and more in-depth investigations will be required.

The ABC Tool can be accessed via the following link: <https://www.interiorhealth.ca/sites/Partners/SeniorsCare/DementiaPathway/MiddleDementiaPhase/Documents/PIECES-ABCtool.pdf>

5.3.2 NDB – Need-driven Dementia-compromised Behaviour model

The NDB model takes as its starting point that the behaviours being exhibited by a person with dementia are not something that should be viewed as some sort of burden for caregivers but rather they are ‘meaningful indicators of unmet need’ (Kovach, 2005). It believes that behaviours are borne out of a caregiver’s inability to comprehend what the person needs and the person with dementia’s own inability to convey what those needs are to those around them. The behaviour is therefore an attempt at communicating that needs are not being met or, in other words, behaviour is a symptom of the problem rather than the problem itself.

The model lists two groups – background factors and proximal factors that lead to need-driven dementia-compromised behaviours and these are shown in Figure 5.1 below.



In the background factors the NDB model takes into consideration a range of potential elements including the physical changes to the certain parts of the brain; how memory and other elements of cognition are affected; one's general health and functional ability and; personality, gender, education, occupation, ability to cope with stress etc.

The proximal factors include: the personal, for example, emotions; environmental factors such as light, noise and temperature; and social environment issues such as the general ambience, mix of staff etc.

The NBC framework is designed to help caregivers organise and integrate the knowledge that they gather about a person, including 'soft facts' about a person's background and the 'hard' empirical and clinical observations. Through the gathering of this knowledge one might gain insight into, and develop strategies for, the trigger(s) causing the changes in a person's behaviour. The model is designed to be flexible so that it can be refined to apply to different Need-driven Dementia-compromised Behaviours.

Summary

In this section we have highlighted two assessment frameworks and two behavioural analysis tools that may prove useful in finding workable solutions for specific issues that might arise. There are other frameworks and tools that could also have been chosen each with their own merits. For example, P.I.E.C.E.S.[™], developed in Ontario, Canada, is described as a "best practice learning and development initiative that provides an approach to understanding and enhancing care for individuals with complex physical and cognitive/mental health needs and behaviour changes." (P.I.E.C.E.S.[™] handbook, 6th edition). It provides a practical framework geared to finding solutions via a rigorous assessment process using a 'whole team', person-centred approach. Another popular framework is the D.I.C.E. Approach[™]. D.I.C.E., which stands for Describe, Investigate, Create and Evaluate uses a person and caregiver approach and is used in a wide range of settings. It allows clinicians to examine the roles played by non-pharmacological interventions as well as medical and pharmacological treatments to arrive at the best outcome for the person.

Other behavioural analysis tools include Dementia Care Mapping (DCM)[™], a system devised by Prof Tom Kitwood at Bradford University. This provides a detailed examination of a person and their interactions with other people and their environment. However, it is a complex tool, reliant on DCM[™] trained 'mappers' spending considerable time observing and recording interactions, followed by a detailed analysis of these interactions or behaviours. The approach requires the full commitment of staff and management and will often require a number of 'mappers' to be formally trained.

6. INTERVENTIONS

This chapter presents information and guidance on a range of specific intervention approaches that may be worth considering when deciding how best to address NCS D presented by people with dementia in any given instance/situation, whether in home/community or institutional settings. Section 6.2 provides an overview of available research evidence as well as recommendations made in various international guidance documents. Section 6.3 then elaborates on a number of the more commonly recommended and/or evidenced interventions identified from these sources.

The better you know and understand the person with dementia the more likely the success of tailored interventions. Many organisations now provide very simple 'life profiles' to assist staff develop a more person-centred approach.

Mary

Things you should know about me

I ran the accounts department for a big high street store

I am also a wife and a mother with three children

I prefer a bath to a shower

I need help to put my shoes on in the morning

I like:

- › Visits from my children
- › My photograph album
- › Classical music
- › Adventure movies
- › Nature
- › Dogs and cats
- › Dark chocolate

Example of a simple 'life profile'

6.1 Selecting interventions

The approaches outlined in the previous section emphasise the importance to carefully examine potential underlying reasons or trigger factors for distressing NCSD before considering whether and how to intervene or try to treat. In many cases, relatively simple adjustments may make a substantial difference; for example, modifications in the physical and social environment, more effective communication between carers and the person with dementia, and efforts to provide pleasurable and engaging activity.

Although this should generally be the first line approach, it is not always easy to identify specific factors amenable to adjustment in ways that effectively reduce or eliminate the presenting NCSD and/or the associated distress. Whilst emphasising the importance of a person-centred perspective, and seeking individualised solutions matched to the person's sense of identity, personality and life history, it is also helpful to identify a menu of specific interventions that have evidence of effectiveness.

This aspect of the guidance draws on a number of sources of evidence, including systematic reviews of international guidance documents and consolidated reviews of the evidence from the very large research literature in this field. This literature generally recognises that simplistic, prescriptive recommendations are neither possible nor appropriate. The complexities in the underlying factors for NCSD mean that an individualised approach to selection of interventions is necessary. Finding the most effective solutions may require trying a variety of approaches in any given case or setting.

6.2 Research evidence

A considerable body of published research is now available on assessments of the effectiveness of a broad range of interventions addressing NCS D. This includes a very large volume of primary studies (including many randomised control trials and other forms of controlled studies) and a substantial number of systematic reviews of these studies. Based on the evidence and guidance reviewed, Table 6.1 presents a listing of some of the more promising interventions for consideration in addressing NCS D. It also includes some other interventions receiving growing attention and with at least some promising evidence. Further information on the research evidence behind these suggested interventions can be found in the Appendix.

Table 6.1 · A range of possible interventions

<p>Psychosocial</p> <ul style="list-style-type: none"> › Meaningful activities › Gardens and gardening › Music therapy and music › Physical exercise
<p>Behavioural-based (covered in Chapter 5)</p>
<p>Environment (covered in Chapter 4.5)</p>
<p>Sensory</p> <ul style="list-style-type: none"> › Aromatherapy › Massage › Light therapy
<p>Assistive technology</p> <ul style="list-style-type: none"> › Telecare and enabling technologies
<p>Other*</p> <ul style="list-style-type: none"> › Animal-assisted, doll therapy, robotic animals etc

* other interventions of growing interest and at least some promising evidence

NCS D covers a broad range of symptoms, and these fall into a number of domains – behavioural, affective, psychotic, and others. Quite different approaches and associated specific interventions may be required for symptoms in the different domain groupings. However, as symptoms within and across domains commonly co-occur for the same person with dementia, it is difficult to make recommendations on what specific intervention to use and when to use them. It is unsurprising, therefore, that guidance in this field tends not to employ prescriptive, decision-making algorithms that map specific interventions to specific symptoms.

Nevertheless, it is important to provide some basis for sorting the various interventions and mapping them towards the NCS D categories and domains. For example, in Australia, the Dementia Collaborative Research Centre – Assessment and

Better Care (DCRC-ABC) evidence review and guidance has grouped NCSD symptom areas into ten categories including agitation, nocturnal disruption and disinhibited behaviours. (see the Appendix for more detail)

Mapping in this way helps to show where the different intervention categories and NCSD symptom areas most coincide, both in their logic/substance and in evidence of intervention effectiveness, and thereby helps to highlight the more promising interventions to try for particular symptom areas. However, as emphasised in Chapter 5, intervention to address NCSD should not be reduced to a simplistic selection and once-off application of a discrete intervention. The realities of NCSD, and of caring for people experiencing NCSD, are much more nuanced than this. Interventions may be helpful not just in responding to NCSD when it arises, but also in preventing or reducing the likelihood of NCSD emerging or worsening. Some categories of intervention (e.g. psychosocial and environmental) have particular potential for both preventative and 'treatment' purposes, as well as a likelihood of having impact across more than one co-occurring symptom area.

6.3 Specific evidence-based interventions

This section provides some further information on the following set of interventions

- › Meaningful activities
- › Music therapy and other music based interventions
- › Gardens and garden therapy
- › Physical exercise
- › Light therapy
- › Aromatherapy
- › Massage and touch therapy
- › Assistive technology and telecare
- › Simulated and robotic therapy
- › Animal assisted interventions
- › Doll therapy

Other therapeutic interventions

- › Validation therapy
- › Reality orientation therapy
- › Reminiscence therapy
- › Lifestory work
- › Cognitive Stimulation Therapy
- › Cognitive Rehabilitation

Meaningful activities



Examples of activities offered:

Individualised activities of daily living: this would include engaging people in the sort of tasks that they would have undertaken in their own homes. This could be as basic as dressing, a task that may, for example, involve staff demonstrating how to put on clothes correctly rather than physically dressing someone. Other activities may include light housework tasks such as dusting or folding laundry or helping prepare elements of a meal.

- › Arts and crafts: this could involve drawing, painting and working with textiles and other materials.
- › Work-related tasks: again this might involve performing household chores, gardening etc.
- › Recreational activities (e.g. games); delivered in groups or individually; delivered by different professionals or a multidisciplinary team.

What does the research evidence say?

Offering personally tailored activities to people with dementia in long-term care may be considered as an intervention for behaviours that challenge. Offering any activities to people with dementia seems to be necessary from an ethical perspective. Personally-tailored activities include an assessment of participants' present or past preferences for, or interests in, particular activities. All studies described positive effects on pleasure and interest along with an improvement in agitation. (*References: Cohen-Mansfield 2006, Mohler 2008, Testad 2014, Travers 2016*)

What are the benefits?

- › helps the person maintain his or her independence for as long as possible
- › helps maintain skills
- › improves self esteem
- › improves the quality of life for the person with dementia and their carers
- › allows the person to express his or her feelings, through art, music, singing and dance

- › bring pleasure to the person with dementia and their carers as they share these moments together
- › provides social contact through social activities and outings, keeping both the person with dementia and their carers in touch with family and friends.

Useful tips

- › Activities do not need to be structured or complicated.
- › Keep activities non-competitive to avoid feelings of failure in the person with dementia if he or she cannot cope.
- › Include quiet time to allow people to rest.
- › Generally it is advisable to plan activities early in the day when the person is more likely to have more energy.
- › Quieter activities are often more effective in the afternoons and early evening, when some people with dementia are more restless.

Useful links

- › https://alzheimer.ie/wp-content/uploads/2018/11/C4_Activities_2015.pdf
- › <https://www.alzscot.org/assets/0000/0266/activities.pdf>
- › <https://www.alzheimers.net/?s=meaningful+activities>
- › www.nhs.uk/conditions/dementia/activities
- › <https://www.betterhealth.vic.gov.au/health/ConditionsAndTreatments/dementia-carers-and-activities>

Music therapy and other music based interventions



Many music related interventions can be facilitated by anyone – a nurse, an activity coordinator, other healthcare professionals, volunteers, family members or, in some cases, a qualified music therapist. The interventions can take place at home, in day centres or in long term care settings.

Music therapy (as opposed to music/singing more generally) is a form of treatment where qualified musical therapists utilise music and/or its components (melody, rhythm, harmony, sound) for specific psychotherapeutic, psychosocial or other purposes. The trained music therapist will work either with a group or individually using music to support and help people express themselves and communicate with others.

A range of less formal applications of **music interventions** and singing are more commonly implemented in dementia care. For those receiving the therapy/intervention it may involve passive listening or active participation; specific music therapy interventions include listening, moving/dancing and singing/playing, sometimes in combination with exercise and reminiscence therapy.

Music can be used in a range of structured or unstructured ways, either individually or in a group, such as:

- › Listening to a live performance
- › Playing instruments or singing/choir
- › Listening to music played through headphones
- › Listening to favourite pieces of recorded music

What are the benefits?

- › Music helps people with dementia express their feelings and ideas
- › It can encourage physical exercise, dance or movement
- › It can encourage social interaction with others, reduce social isolation and promote activity in groups
- › Music can prompt reminiscing. As the long term memory is activated it restores a sense of 'remembered self' a return to fond memories and feelings of calm and security.
- › Singing or playing a favourite piece of music can lessen distress and may be particularly helpful whilst giving personal care offering a useful distraction.

- It can help the person with dementia 'tell their story' and give voice to their personal history.
- Music intervention/therapy can provide a powerful and pleasurable way to communicate and connect with someone, especially when other forms of communication are lost.
- When verbal communication is not possible, music therapy offers musical instruments and improvisation for the expression of emotions, and music listening to evoke changes in mood and responsiveness.

(References : Abraha 2017, Ueda 2013, McDermott 2013, Hulme 2010, Livingston 2014, Victor 2016, Vasionytė and Madison 2013,)

Useful links

- <http://www.localartsireland.ie/our-work/case-studies/arts-health/musical-memories-choirs/>
- https://www.dlrcoco.ie/en/arts/arts-community/musical-memories_
- <http://forgetmenots.ie/>
- <https://musicmemories.bbcrewind.co.uk/>
- https://www.dementia.org.au/search/node/music_
- <https://www.musictherapyireland.com/dementia-care>

Gardens and garden therapy



There are gardening activities that can be carried out by those of all abilities. Levels of activity can be easily adjusted to suit different users, from those who might like to sit back and take in the view, to those who would prefer a more 'hands on' approach. Depending on the size of the garden it might be possible to incorporate a shed, greenhouse or polytunnel that would allow parts of the garden to be used in inclement weather. Verandahs can also create an area, protected from the elements, that will allow people to access the outdoors.

Gardens also provide opportunities for enjoyable forms of physical exercise which help to maintain mobility and flexibility encompassing the use of all motor skills i.e. walking, reaching, bending and planting seeds and taking cuttings. Working in a garden can improve strength and conditioning and helps reduce the risk of osteoporosis. Gardens are known to reduce stress levels and promote relaxation as well as providing stimulation and promoting an interest in nature and the outdoors.

Some suggested activities using flowers, greenery, fruit or vegetables from the garden are as follows:

- › Flower arranging using, living or dead flowers
- › Pressing dried flowers to make pictures, greeting cards or bookmarks
- › using dry lavender or other fragrant flowers and herbs to make lavender bags, moth bags (use thyme, mint, rosemary, sage, sweet marjoram and lavender, for example, which repel moths), herb pillows or pot pourri
- › prepare and eat produce from the garden
- › Simply looking at and talking about flowers, leaves, fruit, vegetables and herbs can be a stimulating activity in itself. The beauty of their colour, shape, texture and smell can be explored and shared

What are the benefits?

- › While actual reasons remain unclear, studies have shown that human beings possess an innate attraction to nature.
- › Being outdoors creates feelings of appreciation, tranquillity, spirituality and peace.
- › Being present in a garden is in itself restorative and actively participating in gardening enhances those feelings and helps a person maintain circadian rhythms (the sleep/wake cycle)

- Being present in a garden helps in the natural absorption of vitamin D when exposed to sunlight for brief periods of time which is important for maintaining healthy bones.
- Specially designed gardens can help maximise cognitive and physical abilities and help to alleviate symptoms such as apathy, confusion and agitation often associated with the condition
- Natural surroundings can have a significant effect on people's health, development and general well-being (Kaplan 1995, 2001)
- Spending time in gardens can improve feelings of well-being and quality of life
- Access to sunlight can boost Vitamin D levels
- Spending time in gardens can improve self-esteem, self-confidence and social interaction when other forms of communication become more difficult
- It can also reduce agitation, pacing and exit-seeking behaviour and the need for psychotropic medication

(References: Abraha 2017, Whear, 2014, Detweiler, Murphy, Kim, Myers, and Ashai, 2009; Detweiler, Murphy, Myers, and Kim, 2008; Murphy, Miyazaki, Detweiler, and Kim, 2010).

Useful links

- https://www.enablingenvironments.com.au/uploads/5/0/4/5/50459523/gardens_that_care.planning_outdoor_environments_for_people_with_dementia.pdf
- <https://www.unforgettable.org/blog/10-ways-to-design-a-dementia-friendly-garden/>
- <https://www.alzscot.org/living-with-dementia/getting-support/accessing-alzheimer-scotland-support/therapeutic-activity/horticultural-therapies>
- <https://www.understandtogether.ie/bloom/>
- <https://www.independent.ie/videos/life/watch-bloom-2019-dementia-sufferers-go-back-in-time-through-50s-style-garden-38160823.html>
- <http://www.newtownsaunders.ie/dementia-friendly-gardens/>

Physical exercise



Exercise is any activity requiring physical effort, carried out to sustain or improve health and fitness. This includes everyday activities such as walking, gardening or dancing, as well as sports and exercises with the specific aim of improving fitness. Other examples of the types of exercise that a person may perform include gardening, housework (such as vacuuming and folding laundry), indoor bowls/skittles, dancing, seated exercises, swimming, Tai Chi, walking, cycling and gym work.

For those in mid-life there is no upper limit to the amount of exercise that one should take. The Health Services Executive (HSE) Guidelines for older people (aged 65+) recommend at least 30 minutes a day of moderate intensity activity, five days a week (or 150 minutes a week). The focus is on aerobic activity, muscle strengthening and balance. This can be divided into shorter sessions throughout the day, with each session lasting a minimum of 10 minutes. For example, it could be a 15-minute walk to the local shops, and then housework or gardening tasks in the afternoon.

There is evidence that physical activity may reduce the risk of progressing to dementia in a person who has Mild Cognitive Impairment (WHO 2019). It is reasonable to think that there may also be benefits in slowing cognitive decline in a person who already has early stage dementia.

For people in the later stages of dementia the ideal amount of exercise will also vary from person to person. People in the later stages of dementia should be encouraged to move about regularly and change chairs, for e.g. when having a drink or a meal. There should be opportunities to sit unsupported (as far as possible) with supervision on a daily basis. A daily routine involving moving around the home can help to maintain muscle strength and joint flexibility.

What are the benefits?

- › The person with dementia needs occupation and meaningful engagement, which exercise provides
- › It helps maintain a healthy cardiovascular system which can reduce the risk of high blood pressure and heart disease
- › It reduces the risk of certain cancers (particularly breast and colon cancer), stroke and type 2 diabetes

- It improves physical fitness – maintaining strong muscles and flexible joints reduces the risk of falls and can help people maintain independence for longer
- Exercise helps to maintain healthy bones and therefore reduces the risk of osteoporosis (a disease that affects the bones, making them weaker and more likely to fracture)
- Physical activity provides opportunities for social interaction which enhances communication and reduces the feeling of isolation
- Exercise creates valuable opportunities to be physically, mentally and socially engaged. This is beneficial to both people with dementia and their care partners
- It can improve confidence, self-esteem and mood.

(References: Abraha 2017, Tible 2017, Thune-Boyle 2012, Forbes 2015, Dimitriou 2018, Maltais 2019, O'Neill 2011)

Useful links

- <https://www.healthpromotion.ie/hp-files/docs/HPM00487.pdf>
- <https://www.alzheimers.org.uk/get-support/daily-living/exercise>
- <https://www.alzscot.org/assets/0000/0168/healthylivingwithdementia.pdf>
- <https://www.betterhealth.vic.gov.au/health/ConditionsAndTreatments/dementia-activities-and-exercise>
- <https://www.hse.ie/eng/about/who/healthwellbeing/our-priority-programmes/heal/physical-activity-guidelines/>

Light therapy



Circadian rhythm refers to the 24-hour rhythm (rest-activity and sleep-wake cycles) that motivates activity in humans, plants and animals. It plays a significant role in controlling biological functions such as sleep cycle, eating habits, hormone release and temperature regulation. Disturbances in this cycle are a common pathological characteristic of dementia. Light therapy is based on the principle that exposing the retina to a 24-hour light/dark pattern can modify the body's circadian rhythm. It is an effective and non-invasive method of improving sleep patterns. Studies have shown that it aids conditions of depression, agitation and also shows improvements in older adults with dementia.

It is administered through patterned exposure to daylight or to specific wavelengths of light using polychromatic polarised light, lasers, fluorescent lamps, or in some cases, bright, full-spectrum light. The light used is brighter than regular indoor light but not as bright as sunlight.

What are the benefits?

- Light therapy offers several potential but modest benefits with regards to improving sleep efficiency in Alzheimer's disease
- Regular light exposure can reduce sleep disturbances or night time wakefulness
- Light therapy may bring about modest improvements in certain mental health parameters of Alzheimer's disease such as: depression, dysphoria, eating disorders
- Light therapy provides a moderately efficient mode of improving cognition in people with Alzheimer related dementia
- Their mood, cognitive and non-cognitive functions showed some positive changes post-exposure to bright light in clinical studies

(References: Forbes 2014, Mitolo 2018, Ancoli-Israel 2003, Sloane 2007, Satlin 1992, Glenna 2005, McCurry 2011, Lovell 1995)

Useful links

- <https://www.alzheimers.org.uk/about-dementia/treatments/alternative-therapies/bright-light-therapy-and-dementia>
- <https://www.verywellhealth.com/bright-light-therapy-and-its-use-in-alzheimers-disease-98668>
- <https://www.salubrainous.com/light-therapy-for-alzheimers/>

Aromatherapy



Aromatherapy uses scents to promote health and wellbeing, with postulated impacts on mood and mental wellbeing more generally. The approach typically uses essential oils distilled from plants, often administered through massage therapy although delivery may also be through aromatic baths or vaporisation. It has been used to treat emotional disorders, such as stress and anxiety, as well as in a range of wider applications such as alleviation of pain and nausea, and in promoting sleep. Apart from the perceived benefits to health and wellbeing, factors influencing aromatherapy's popularity are that it is non-invasive, readily available and relatively inexpensive, pleasant to use, and usage (including self-administration) does not necessarily require prior consultation with a health-care professional.

What are the benefits?

Essential oils and dementia

Lavender – One of the essential oils most used in studies of the effects of aromatherapy and massage on people with dementia.

- › It is said to be calming and to balance strong emotions
- › Is believed to enhance mood and may also be beneficial in enhancing better sleep

Lemon balm – (*Melissa officinalis*) the most studied and, is suggested to be, one of the most effective of the essential oils for people with dementia.

- › It may help to induce calm and relaxation
- › It may reduce anxiety and insomnia

Peppermint

- › Used to both stimulate the mind and calm the nerves
- › It is said to rectify absent-mindedness and improve memory
- › Used in the morning it can energise a person and stimulate appetite

Rosemary

- › May stimulate the body and mind and improve memory
- › There is some evidence that rosemary oil improves cognitive performance in speed and accuracy measures
- › It is said to lead to improvement in mood

Bergamot

- › Is believed to have a calming effect
- › May help to relieve stress and anxiety
- › May also relieve mild depression and insomnia

Ylang Ylang

- › Relaxing and stress relieving, but may impair memory so needs to be used with caution

Other oils

- › Ginger (the oil as well as the spice and the fresh root), is beneficial for digestion and appetite
- › Oregano oil has anti-microbial, antibacterial, anti-parasitic, anti-viral, and anti-fungal properties
- › Frankincense, Chamomile, Eucalyptus, Thyme and Sandalwood are known to have anti-inflammatory properties

(Ref: Baggoley 2015, Abraha 2017, Forrester 2014, Fung 2012)

Massage and touch therapy

The general term 'massage therapy' describes a wide variety of techniques that vary in the manner of application of the touch, pressure and intensity of the intervention (Baggoley, 2015). It is generally performed by 'massage therapists' to deliver therapeutic massage therapy and/or administer body treatments for relaxation, health, fitness and remedial purposes. In health and long-term care settings hand massage would be the most common form of intervention.

Useful links

- › <https://www.dementiauk.org/understanding-dementia/advice-and-information/complementary-therapies/aromatherapy/>
- › <https://www.alzheimers.org.uk/about-dementia/treatments/alternative-therapies/aromatherapy-massage>
- › <https://best-alzheimers-products.com/alternative-therapy-for-alzheimers/aromatherapy-for-alzheimers>

Assistive technology and telecare



By adopting the terminology now most commonly utilised in Irish research and practice in this field (based on Cullen and Keogh, 2018; Cullen et al, 2016) we can make the distinction between Assistive Technology and Telecare.

‘Assistive technology’ refers to stand-alone equipment for use by the person with dementia. Examples include automatic clock/calendars, simple to use phones, reminder devices etc.

‘Telecare’ refers to systems that alert carers when the person with dementia has a need or is at risk. Systems may be active (where the user actively triggers an alert when they need help) or passive (where sensors trigger the alert when a risky situation arises; they may be linked to an external monitoring centre or installed entirely within the home).

With regards to Assistive Technology (AT) the International Standards Organisation (ISO) defines AT (‘Assistive Products’) as: “Any product (including devices, equipment, instruments and software), especially produced or generally available, used by or for persons with disability: for participation; to protect, support, train, measure or substitute for body functions/structures and activities; or to prevent impairments, activity limitations or participation restrictions.” (ISO 2016).

AT, when applied correctly, can greatly benefit people living with a dementia, provided it is used in an ethical manner and provided the choice of product is based on the assessment of individual needs and dementia. It is vital to remember that AT can never be a replacement for human contact and care that is underpinned by person-centred principles. The advance of technology in our societies brings with it many benefits but also threats, and AT should only be used to support people living with dementia to undertake tasks they might otherwise struggle with.

Examples of how Assistive Technology might help people with a dementia maintain independence and also to remain safe include:

- Locating missing objects such as a wallets, keys and handbags
- Helping with directions
- Telling the day, date and time
- Maintaining contact with family and friends
- Reminding people when to take their medications
- Helping to locate people who have lost their way

AT is not a panacea for all the difficulties that a person with dementia might face and it is unlikely to have suitable applications at all stages of the illness but it can promote continued independence and quality of life beyond a time when a person may have required increased formal supervision.

The role and scope of telecare has grown exponentially since the days of the simple 'pendant alarm'. Although telecare is also designed to help an older person or a person with a disability remain independent for longer its purpose is fundamentally different. While AT is designed to assist people to do things or to minimise difficulty with tasks, telecare is more about prevention and the monitoring of risks. Telecare systems are based around a telephone connection both from a fixed landline and, increasingly, via a mobile connection. The more advanced telecare systems now have multiple sensors that can notify a monitored call centre, or a family carer, when an alarm is raised. These sensors can cover a number of different scenarios and this can include:

- › Bed and chair occupancy sensors
- › Monitored heat and smoke detectors
- › Fall detectors
- › Carbon Monoxide detectors
- › Property exit sensors
- › Flood detectors
- › GPS tracking or 'geo-fencing'

The role of monitoring devices does raise ethical issues and considerations around their use, particularly in the area of consent. With the Assisted Decision-Making Capacity Act (2015) providing laws for Advanced Healthcare Directives these ethical issues may be eased as people make decisions about their future medical treatments.

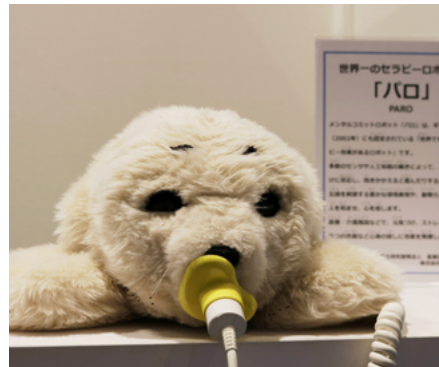
There are now a number of Memory Technology and Resource Rooms situated in each Community Healthcare Organisations (CHO) in the country. They are staffed by healthcare professionals who are able to offer expert advice on equipment, both AT and telecare, which may help people with particular difficulties that they are experiencing or enhance a person's ability to remain independent and safe within their own home. More information on Memory Technology and Resource Rooms can be found at: <https://www.understandtogether.ie/training-resources/helpful-resources/memory-assistive-technologies/>

(References: Davies 2013, Cahill 2007, Carswell 2009, Cullen 2015, Cullen 2016, Graham 2011, Keogh 2010, NICE 2015, Poole 2006, Topo 2009, Woolham 2005)

Useful links

- › <https://alzheimer.ie/get-support/how-technology-can-help-you/>
- › <http://www.dementiacircle.org/>
- › <http://www.assistireland.ie/eng/>
- › <https://alzheimer.ie/wp-content/uploads/2018/11/ASI-Assistive-Technologies-Brochure-website-4.pdf>
- › https://www.cochrane.org/CD009627/DEMENTIA_assistive-technology-memory-support-dementia

Simulated and robotic therapy



Simulated and robotic pets can be used as part of engagement or leisure activities to support people living with moderate to severe dementia. They may provide comfort and help engage people living with dementia who show signs of social isolation, reduced communication, apathy or agitation. Research has shown that the use of simulated and robotic pets can provide many positive outcomes for the person with dementia, including reducing the frequency and severity of behaviours that challenge. They can stimulate people with dementia to be more communicative and enable caregivers and family members to make contact with them. The use of robotic pets in people living with dementia appears to induce a sense of calm and revitalisation, along with reducing anxiety and/or confusion, loneliness and/or depression.

Based on practical experiences it seems that pet robots have the most beneficial effect on people in the later stages of dementia, on people with dementia who have or have had (domestic) animals themselves and who have difficulty in communicating.

Recommendations for the healthcare professional prior to introducing the robotic pet

- It is important for the healthcare care professional to understand how the robot works and how it should be applied in practice.
- This knowledge base will ensure that the robot is used in the most effective way during the activity.
- Equally, the knowledge and experience of the healthcare professional is a necessity when working with the pet robots.
- When and how to use the robot depends greatly on the insight of the healthcare care professional.
- It is recommended that a protocol is devised for the use of the pet robot within the health care institution, so that professionals all use the same method.

Precautions and considerations prior to introducing the robotic pet to the client

- › To ensure the activity is suitable, conduct an assessment before introducing the pet to identify any history of negative experiences with animals, such as physical injury, allergy, or abuse.
- › Don't impose the activity on people who haven't shown any interest, as not everyone will respond to it.
- › Pet robots do not always have the desired effect on everybody and it is difficult to pre-identify which person is or is not suitable for the introduction of a robot.
- › Pet robots are in principle suitable for everybody, as long as it matches the needs and wishes of the person.
- › In practice a thorough knowledge of the person's life-story and situation from the care professional is strongly recommended.
- › Be mindful of the person's preferences. For example, cat lovers may not engage with dogs while some people might love all animals.
- › Animal representational toys should be interactive and as life-like as possible in terms of appearance, weight, sound emitted, smell and texture.
- › Response to the activity may vary. If the activity doesn't work initially, you could try reintroducing the activity at a later stage – six months later, for instance.

(References: Leng 2019, Smitsa 2015, Heerink 2013)

Useful links

- › <https://dementia.com.au/download/?fdid=69EB1B90680BCB1602D3242B0B546A95>
- › https://www.dementia.org.au/sites/default/files/2.04_Robotic_Pets.doc_2012.pdf
- › <https://www.heymylo.ie/>
- › <http://www.parorobots.com/>

Animal assisted interventions



Animal-Assisted Therapy (AAT) refers to goal-directed therapy and part of a specific treatment plan individually adapted to help a person with dementia in meeting specific needs coordinated by a professionally trained person who is certified. AAT is designed to promote improvements in human physical, social, emotional, and cognitive functions, and can be provided on an individual or group basis, with documentation and evaluation of the process and outcomes. (*American Veterinary Medicine Association [AVMA], 2016, Yakimicki et al 2019, Lai et al 2019*)

Animal-Assisted Activities (AAA) on the other hand are informal recreational or motivational activities where an animal is introduced by a licensed, unlicensed, or volunteer person for recreation, education, to enhance quality of life and bring enjoyment to a person's life (AVMA 2016).

Both AAA and AAT have been successfully used in the care of people with dementia. Animals commonly used in Animal Assisted Therapy/Activities include cats, dogs and/or birds, but horses and other animals can also be used depending on personal client needs. AAA/AAT may not be suitable for every person with dementia, but the evidence does support the fact that for some people, animal interactions can provide an enriching activity with documented results. Long-term care staff along with family members can be positively impacted by the implementation of AAA/AAT in their facility.

What are the benefits?

- › animal interaction has been shown to reduce agitation, depression and aggression in people with dementia enhancing their quality of life
- › increases social interaction and enhances nurturing behaviour in people with dementia
- › improves motivational and cognitive functioning of people with dementia
- › can have a strong positive effect on physical activity levels, dietary intake and quality of life
- › provides an opportunity for people with dementia to express their emotions
- › provides meaningful communication opportunities through interacting with and talking about the animal

- › provides a sense of validation, role and purpose by taking care of and communicating with the animal
- › provides opportunities for reminiscence about past pets, stimulating long and short term memory
- › provides tactile/sensory experiences that elicit a sense of comfort and security
- › promotes expression of positive social behaviours including smiling, laughing and eye contact

Individuals most likely to benefit

- › Individuals who have previously enjoyed looking after domestic pets or being around animals
- › Individuals with early stages of dementia may express interest or enjoy looking at, walking, stroking or brushing the pets
- › Those who have no known allergies to animals
- › Those who have some vision and hearing loss and are in need of tactile stimulation
- › Those who have no known fear or intense dislike of domestic pets or animals
- › Those who have no history of having been abusive toward animals

Useful links

- › <https://www.verywellhealth.com/how-does-pet-therapy-benefit-people-with-dementia-98677>
- › <http://dementiadog.org/>
- › <https://www.alzheimers.net/2013-05-17/how-can-pets-benefit-alzheimers-patients/>
- › <http://heritagehomecare.ie/pet-therapy-for-dementia-sufferers/>
- › <https://www.alzheimers.org.uk/blog/can-caring-for-a-pet-help-a-person-with-dementia>
- › <http://animaltherapy.net/what-is-aataaa/>
- › <https://dementia.com.au/resources/library/care-support-guides/animal-assisted-engagement-in-dementia-care.html>
- › <https://www.hse.ie/eng/about/who/healthwellbeing/infectcont/sth/gl/ipcc-guidelines-section-14.pdf>
- › <https://irishtherapydogs.ie/>
- › <https://animaltherapyireland.org/page/show/22/care-centres.html>
- › <http://www.ohmydog.ie/read/irish-therapy-dogs/>

Doll therapy



The need to give and receive love is an integral part of our existence. The structured use of dolls can provide an avenue for people with dementia to give and receive unconditional love. Doll therapy is a controversial issue with claims that it is infantilising and inappropriate (Boas, 1998) or deceitful and a breach of trust (Cayton, 2001). Others argue that it fulfills some form of attachment need (Miesen, 1993) and may benefit people with dementia (Stephens et al, 2012). If being used, doll therapy should be introduced with caution as it may not be suitable for everyone. It is important to identify the person's parental history and if there were any traumatic events that the person may have experienced. For e.g. if a woman experienced a miscarriage or was unable to have her own children she may find a doll distressing.

What are the benefits?

- › Taking care of the doll can give the person a sense of purpose and validation which in turn can lead to improvements in alertness, activity levels and in general communication with others.
- › Dolls have often been used as an alternative to medication to reduce the impact of behaviours that challenge along with unmet needs, such as: social withdrawal and apathy, vocalising, aggressive behaviour, agitation and restlessness, wandering and intrusion.
- › Some people with dementia seem to get satisfaction and a sense of calm from just holding or simply being with the doll. The sensory experience provided by the doll can provide the person with a sense of comfort and security.
- › It may act as a reminder of when they cared for their young children or simply generate pleasant feelings of affection and reminiscence along with an opportunity to express feelings and emotions.
- › This can facilitate structured reminiscence sessions in both individual and group formats
- › It can provide an avenue for both healthcare professionals and family members to make a connection with the person with dementia

Who is most likely to benefit?

- › Both men and women can benefit from the use of doll therapy, depending on the level of interest they show.
- › People in the earlier stages of dementia, who may like to observe, hold and care for the doll but are less likely to identify it as real.
- › People with moderate to severe dementia or a mixed dementia, who are more likely to perceive the doll as being a baby.
- › People with dementia who may be experiencing delusions or hallucinations about their baby crying or frequently looking for their baby.
- › People with dementia who have returned to past life memories of parenthood, when they had previously enjoyed being around children or babies.

Selecting the doll

- › In selecting the most suitable doll, it is important to choose the most realistic one in terms of appearance and size. In general, dolls with soft bodies but firm hands feet and heads provide the most realistic 'feel'.
- › The type of doll selected should match the person's cultural background and social history. For example, consider choosing a doll with the same skin colour as the person.
- › Ensure that the doll is appropriately clothed for its purpose. A doll that is poorly presented shows little regard for both the person with dementia and the reasons for introducing the doll.

Remember that healthcare staff should not use dolls as the only source of activity for the person.

Useful links

- › <https://www.alzheimers.net/8-6-14-doll-therapy-alzheimers/>
(Pros and Cons of Doll Therapy for Alzheimer's)
- › <https://www.dementiauk.org/the-use-of-dolls-in-dementia-care/>
(The use of dolls in dementia care)
- › <https://www.dementia.org.au/files/WA/documents/2.00%20Guidelines%20for%20Use%20of%20Dolls%20and%20Mechanized%20Pets%20as%20a%20Therapeutic%20Tool.pdf>
(Guidelines for Use of Dolls and Mechanized Pets as Therapeutic Tools)

Other therapeutic interventions

Validation therapy



Validation therapy initially developed by Naomi Feil in the 1960s is a way of approaching people living with dementia with empathy and understanding. The basic idea behind validation therapy is that people who are in the late stages of life may have unresolved issues that determine their behaviours and emotions. The way healthcare professionals or family members react to these behaviours and emotions can either exacerbate or help resolve them. Validating a person's feelings is one aspect of validation therapy. It also focuses on helping the person work through the emotions behind the responsive behaviours. These behaviours are perceived essentially as a way of communicating those emotions, especially in people with memory loss, confusion, disorientation, and other symptoms of dementia. Validation can help build the person's sense of trust and security, while reducing their anxiety. A good understanding of the person and their situation is essential.

Useful tips

Validation is a three-step approach used in dementia care to communicate an understanding of the emotional state of people with dementia. The steps involved in validation are:

- Respectfully acknowledging or validating the feelings the person is experiencing, e.g., "You sound upset/worried/angry..."
- Offering to help the person with their concern by providing emotional support and reassurance, e.g., "I would be worried too if I could not find my daughter."
- Gently redirecting the person's attention to something more pleasant by reminiscing, changing the topic of conversation, the activity and/or environment they are in.

Useful links

- <https://dementia.com.au/resources/library/care-support-guides/understanding-psychosocial-approaches-validation.html>
- <https://www.verywellhealth.com/using-validation-therapy-for-people-with-dementia-98683>
- <https://www.alzheimers.net/2013-11-07/validation-method-for-alzheimers/>
- <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD001394/epdf/full>

Reality orientation therapy



Reality Orientation Therapy (RO) works through the presentation of orientating information (e.g. time, place and person-related) which is thought to provide the person with a greater understanding of their surroundings, possibly resulting in an improved sense of control and self-esteem. There has been criticism of RO in clinical practice, with concerns that it has been used in a mechanical way and has been insensitive to the needs and emotions of the individual. There is also a suggestion that constant relearning of information can in fact exacerbate mood and self-esteem problems. RO is more effective in people in the early stages of dementia as orientating them to their environment can slow the cognitive effects of dementia delaying the need for nursing home care.

What are the benefits?

- › Significant positive effects have been reported in studies of RO on cognition and behaviours that challenge in people with dementia.
- › More research is required to examine which features of RO are particularly effective.
- › It is unclear how far the benefits of RO extend after the end of treatment, but it appears that a continued programme may be needed to sustain potential benefits.

Strategies for reality orientation

- › Refer to calendars and clocks, display the day, date, time of next meal, and even weather. You must remember to change it every day!
- › Buying daily newspapers and discussing current events (discard old newspapers).
- › Place picture signs on each door to label the purpose of each room/cupboard.
- › Making sure that everyone wears name badges, if the person is in residential care.
- › Frequently use the person's name in conversation, and refer to the day of the week as often as possible.
- › Ask questions about photos or other decorations.

Useful links

- › <https://www.verywellhealth.com/treating-alzheimers-disease-with-reality-orientation-98682>
- › <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD001119/epdf/full>
- › <https://quietdementia.wordpress.com/2015/03/01/the-reality-orientation-approach-vs-the-validation-approach/>

Reminiscence therapy



Reminiscence Therapy (RT) stimulates memories and interpretations in the present of life events from some point in the persons' past, usually the distant past from childhood and adolescence as these memories have been well learned. Reminiscence therapy involves discussion of past experiences, events and activities with family or others. The intervention may utilise materials such as photos, books, newspapers or other items familiar to the person with dementia. The aim is to inspire reminiscence and the benefits for the person with dementia from the sharing and valuing of their experiences.

What are the benefits?

- › Reminiscence therapy can give people with dementia a feeling of success and confidence because it's something they still have the ability to do.
- › It gives them an opportunity to talk and share something meaningful rather than just listen.
- › Talking about happy memories of the past also brings joy, which is especially helpful if the person, as an adult is having difficulty with everyday life – it helps them cope with stress.
- › Consequently, reminiscence therapy for people with dementia helps reduce depressive symptoms and increases self-esteem and psychological well-being dimensions.
- › RT gives people with dementia a sense of value, importance, belonging, power, and peace.
- › It can also help reduce injury to self-image, and it can create a feeling of intimacy and give special meaning to engagement with others improving and enhancing social involvement and connectiveness.

Lifestory work



Due to challenges with memory loss and communication, a person living with dementia sometimes needs help to communicate important aspects of their identity such as background, interests and experiences along with who and what is important to them. Lifestory work (LSW) which is a type of reminiscence, may enable the person with dementia retain their sense of identity and empower them to reflect on their achievements and experiences at a time when there may be feelings of loss or depression. LSW is a record of someone's life and experiences presented in a tangible form. It is a therapeutic use of residents' biographies and a source for reminiscing. It is an integral part of person-centred care.

Purpose of lifestory work

- › To prevent a sense of loss of identity that can be experienced by a person with a dementia
- › To give Carers an understanding and appreciation of the person and their life
- › To provide a resource when developing individualised activities for the person

What are the benefits?

- › enhances well-being;
- › improves mood and some components of cognitive function
- › reduces disorientation and anxiety;
- › improves self-esteem, memory and social interaction

In general, there are better outcomes from lifestory work in areas which have:

- › strong and consistent leadership,
- › higher ratio of qualified staff to unqualified staff,
- › context or culture that supports change and encourages communication.

Lifestory work has the potential to enhance person-centred care in long-term facilities.

The process of implementation of life-story work requires education, time and resources and a commitment from service providers and managers.

Methods of collecting lifestory work

- › Lifestory books – These can come in many different formats which vary between different healthcare settings. Relevant information can be easily transferred into different versions. It is possible to design a more individual template if needed.
- › Collages – these are less adaptable but work well when using lots of photographs and images to encourage reminiscence and are particularly useful for people in the later stages of dementia. Ensure high contrasting colours between the background and the photographs/images for easy recognition.
- › DVDs – this is a good way to record visual information. Use pre-recordings of family events or experiences or adventures that the person with dementia may have. These may also include messages from the person or his/her own voice recorded.
- › Reminiscence or memory boxes – these are useful for all people with dementia but especially for those with sensory impairments.
- › Apps – there are a number of Apps to help save and share memories of special places that can upload photos, mark their location and attach messages and/or voice recordings.
- › Other electronic formats – these can be useful for keeping the lifestory safe and allow ongoing changes to be made.
- › Personal profile documents – These include a detailed background as well as a synopsis of the person with dementia. These can be used in addition to more detailed lifestory work examples. The shorter version can be very useful if the person with dementia requires admission to a hospital setting.

Useful links

- › www.lifestorynetwork.org.uk
- › <https://www.dementiauk.org/wp-content/uploads/2017/03/Lifestory-compressed.pdf>
- › <https://www.alzscot.org/living-with-dementia/getting-support/accessing-alzheimer-scotland-support/therapeutic-activity/reminiscence-therapy>
- › <http://www.makinghaytheatre.ie/>
- › <https://www.alzheimers.org.uk/dementia-professionals/resources-professionals/memories-are-made-reminiscence-activities-person-centred-care>
- › <https://www.alzheimers.org.uk/categories/treatments-and-therapies/reminiscence-therapy>
- › <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD001120.pub3/full>

Cognitive Stimulation Therapy



There are a number of interventions to help people living with dementia improve their memory and thinking skills to enable them to cope better with memory loss. Cognitive Stimulation Therapy (CST) is one such intervention which appears to have the most effect (Agguire et al 2013, Alves et al 2013). CST involves a series of structured individual or group sessions of a recommended 7 week duration with each session lasting for approximately 45 minutes and held twice weekly. To make sure that there is continuity between each session the same structure is used. For example, there is a warm-up activity, a song and a 'reality orientation board' which has information on the group, details including date, time, place, and weather. CST can be carried out by any healthcare worker who has worked with people with dementia and has undergone specific training in CST. CST groups can take place in settings such as residential homes, hospitals or day centres.

The sessions are intended for people with mild to moderate dementia. They are designed to be relaxed, fun and to create opportunities for people to learn, express their views and work with others in a sociable setting. The sessions cover a range of activities to stimulate thinking, memory and to connect with others such as discussing current news stories, listening to music or singing, playing word games, doing a practical activity e.g. baking which involves measuring ingredients and following a recipe. A maintenance programme of CST is recommended once the initial seven weeks of the CST programme is completed and follows a similar structure to the initial programme.

What are the benefits?

- › CST has been found to help the memory and thinking skills of people with mild to moderate dementia.
- › People with dementia who participate in CST report improved quality of life
- › The benefits also relate to the positive experience of being in a group, and the positive impacts of participation on everyday life.
- › CST appears to be particularly effective in promoting language function, and may therefore help with communication and conversation, enabling the person with dementia to express their opinion, which in turn may impact positively on preference revelation and well-being.

One of the most comprehensive and thoroughly researched CST interventions is the *Making a Difference CST Programme* (<http://www.cstdementia.com/>), developed at University College London (UCL), following the MRC framework for the development of complex interventions (Aguirre, Spector and Orrell, 2014). There are specific principles which must be adhered to when using the programme, including mental stimulation, opinions rather than facts, triggers to aid recall, continuity and consistency between sessions, engagement and involvement, inclusion and fun. The programme is now used around the world in approximately 29 countries. Cogs Club is another intervention developed by Jackie Tuppen to provide CST for people with dementia (<https://www.cogsclub.org.uk/home/>). Cogs Club, like CST, is structured and uses thematic sessions, but differs from CST in that the one-hour session is extended to a day of activity, music and fun. NICE guidance recommend the use of group cognitive stimulation as a form of dementia management, regardless of drug treatment and it is considered a standard post-diagnostic support that should be offered routinely to people with dementia (Keogh et al., 2019)

Cognitive Rehabilitation



Difficulties with memory or cognition can often interfere with a person's ability to carry out certain tasks or routine activities of daily living for example, the ability to remember peoples' names, alarm or phone numbers, or how to use household appliances for e.g. washing machine or dishwasher. In some cases, people may not have any particular area of concern, but may want to address in general their memory issues. Interventions can therefore focus either on direct real-life, everyday situations or on more general rehabilitative activities.

One recommended form of CR supported by the scientific evidence is *individual goal-oriented cognitive rehabilitation*. In this form of CR people with dementia (+/- family carers) work together with a trained health professional over a number of sessions to identify goals that are personally relevant and seek to achieve these by devising and implementing strategies. Goals identified may include remembering recent events, reducing repetitive questioning, remembering people's names, or upcoming events (Clare et al. 2003). Assistive technology or memory aids may be used to provide environmental prompts.

Another form of CR is *Home-based Memory Rehabilitation (HBMR)*, an Occupational Therapy-led programme of memory rehabilitation for people with early stage or mild dementia (McGrath and Passmore, 2009). The focus is on structure and repetition to encourage new learned behaviours in early stages of dementia, and promotes habits and routines, with the understanding that these are more likely to be remembered as memory loss continues. The HBMR intervention is structured around six sessions which take place in the person's own home. Each session focuses on a specific topic, e.g. remembering priorities such as taking medication, remembering what people have said, coping in social situations, keeping the brain healthy, orientation and driving. During each session, prompts are given and tactics to compensate for memory difficulties are practiced. External memory aids including a memory book, medication checklist, calendar and memory board are introduced consecutively. After the intervention ends, review meetings are held with participants at regular intervals. The primary outcome measure for this programme is the number of strategies in use at three months. Findings are that intervention participants are using an average of six strategies at three months compared to an average of two at initial assessment.

TCD in collaboration with the ASI devised a manual to provide healthcare professionals with strategies and techniques for cognitive rehabilitation in people with dementia to optimise management of their daily lives and activities (<https://alzheimer.ie/wp-content/uploads/2019/07/2015-Cognitive-Rehabilitation.pdf>)

What are the benefits?

The results of studies on the benefits of individual, goal-oriented CR in people with dementia have shown that people with dementia function better and more independently in relation to goals targeted in the therapy (Clare et al., 2019)

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APPENDIX

Interventions: additional research information

The following section summarises the evidence as available in the research literature, and in guidelines.

Existing research literature

For the purposes of this guidance we have drawn especially on two systematic reviews of existing literature. One was an evidence review for the United States Veterans Health Administration to support policy and practice across its programmes (O’Neil et al, 2011). This is useful because of the effort to translate the scientific research evidence into actionable guidance for the Veterans Administration services. The other was carried out by Abraha (2017) was an overview of the findings for behavioural-oriented approaches and for a range of sensory and other approaches. The tables below highlight their findings.

Promising interventions identified in O’Neil et al (2011)

Massage/Touch/Other sensory therapies: The limited body of evidence suggests that, compared with no treatment, these may have beneficial effects. Some evidence exists for effectiveness of some sensory interventions (aromatherapy, thermal bath, calming music, and hand massage) in decreasing agitation, but with substantial variability in specifics of the interventions, duration of exposure, and outcomes measured.

Music Therapy (for agitation): Well-conducted studies are lacking, but music interventions have potential for reducing agitation in people with dementia in the short term.

Behaviour management techniques: Evidence provides some support for behaviour management techniques as effective interventions for behavioural symptoms. Mixed study results, the variety of specific interventions across studies, and methodological concerns suggest a need for additional research.

Exercise (for sleep): The most consistent evidence showed that exercise increased sleep duration and decreased night-time awakenings; impact of improved sleep on distal health outcomes remains uncertain; may be an additional benefit to caregivers disproportionately affected by dysfunctional sleep.

Assistive technologies (for wandering): In nonrandomized studies, tracking devices, motion detection devices, and home alarms were generally effective in detecting wandering and locating lost patients.

Abraha et al (2017) – review of reviews

Aromatherapy: A Cochrane review found inconsistent effects of aromatherapy on measures of agitation, behavioural symptoms and quality of life (Forrester et al, 2014). Another review covering eleven studies (Fung et al, 2012) showed some promising evidence but results were not consistent across studies.

Massage and touch therapy: A Cochrane review found a limited amount of reliable evidence available for the potential for massage and touch interventions for two specific applications: hand massage for the immediate or short-term reduction of agitated behaviour, and the addition of touch to verbal encouragement to eat for nutritional intake. Another review (Moyle et al, 2013) found only one reliable study that provided evidence to support the use of massage as a non-pharmacological approach to managing agitation in older people with dementia.

Light therapy: A Cochrane review evaluated the effectiveness of light therapy to improve cognition, activities of daily living (ADL), sleep and NCSD (Forbes et al, 2014). The review found no effect of light therapy on cognitive function, sleep, NCSD (for example agitation), or psychiatric symptoms associated with dementia, and the authors found insufficient evidence to justify the use of bright light therapy in dementia. A more recent systematic review assessed the evidence on light therapy specifically for sleep-related issues, covering both general sleep problems and sleep problems related to Alzheimer's disease and dementia (van Maanen et al, 2016). The review found light therapy was effective in the treatment of sleep problems.

Sensory gardens and horticultural activities: A systematic review covered quantitative and qualitative studies on the impact of gardens and horticultural therapy on the mental and physical wellbeing of residents with dementia in nursing homes and specialised dementia care facilities (Whear, 2014). Although the evidence base was very limited and generally poor quality, the authors concluded evidence is promising for positive impacts on levels of agitation in care home residents with dementia enabled to spend time in a garden.

Music therapy: A high quality review included nine RCTs and nine controlled trials (Ueda et al, 2013). Specific music therapy interventions included listening, moving/dancing and singing/playing, sometimes combined with exercise and reminiscence therapy. This review concluded that music therapy was effective in reducing behavioural symptoms (found in six RCTs and five controlled studies), and also in reducing depression (four RCTs and five controlled studies) and anxiety (eight studies). Another review of music interventions included a meta-analysis and reached somewhat different conclusions (Vasiontye and Madison, 2013). It found a significant effect on cognition and on physiology, but not on behaviour or affect. Part of the explanation for the discrepancies may derive from the different review methodologies as well as from the broader scope of the second review covering a wide range of musical interventions and not just music therapy as defined above.

Existing guidance/guidelines

Existing international guidance and guidelines sometimes present their recommendations structured according to type of intervention and sometimes by the symptom area targeted. Both perspectives are helpful and are covered in the overview and synthesis below.

The following table presents a summary of the findings of three systematic reviews of published guidelines, which outline the most consistently recommended interventions for BPSD. These reviews found that available guidelines cover a myriad of approaches and particular interventions, with a lack of consistency in their coverage and/or recommendations, and that this makes it difficult for practitioners to select a specific approach (Ngo et al, 2015). Although guidelines often referred to the importance of non-pharmacological interventions for BPSD, confidence in the evidence available for specific interventions was weak. Recommended interventions vary across guidelines, and guidelines quite often give conflicting appraisals of the same evidence base. Little guidance is available on the practical implementation of interventions (Azermani et al, 2012). However, despite inconsistency in the specific interventions recommended, most guidelines agree that psychosocial interventions are a safe first-line treatment for neuropsychiatric symptoms (Vasse et al, 2012).

Most consistently recommended interventions identified in systematic reviews of guidelines		
Vasse et al (2012)	Ngo et al (2015)	Azermani et al (2012)
<p>Most frequently recommended (psychosocial) interventions:</p> <ul style="list-style-type: none"> › Physical activity › Carer-focused interventions › Multisensory/Snoezelen › Behaviour management 	<p>Sufficient agreement and relatively frequent recommendation for:</p> <ul style="list-style-type: none"> › Environmental modifications › Music therapy › Massage therapy 	<p>Sufficient agreement on recommending:</p> <ul style="list-style-type: none"> › Music therapy › Behaviour management

Symptom-focused guidance

In Australia, the Dementia Collaborative Research Centre – Assessment and Better Care (DCRC-ABC) developed a suite of guidance materials for a range of target groups and purposes (Dementia Support Australia <https://www.dementia.com.au/resources/library>). They adopt a modular approach, presenting extensive information and evidence review on interventions for a range of specific areas of NCSD. The following table presents a high-level summary of the main points presented in the guidelines.

Interventions suggested for different NCSD domains (DCRC-ABC, Australia)

Aggression: Individualised psychosocial interventions may be effective; some support demonstrated for a range of specific interventions.

Anxiety: Multicomponent interventions provide best evidence for psychosocial management of anxiety in dementia. This group includes interventions which target environmental, biological and psychosocial factors contributing to anxiety. Where secondary to other psychological issues, treatment should target the primary problem.

Agitation: Individualised psychosocial interventions may be effective; music interventions provide best evidence.

Apathy: Psychosocial interventions have potential to reduce apathy. Therapeutic recreation, particularly when provided individually, has the best evidence.

Depression: Individualised psychosocial interventions as first line approach, possibly along with medication where indicated. Support for selected psychosocial and environmental interventions, with exercise and behavioural approaches having best evidence.

Disinhibited behaviours: Management requires identification of potentially modifiable factors; limited evidence so needs addressing on a case-by-case basis. Behaviourally-based strategies may be useful to discourage, and psychoeducation/psychotherapy may support family and care staff.

Nocturnal disruption: Management requires identification of potentially treatable factors that contribute – pain, hunger, thirst, infection and/or poor sleep hygiene. NITE-AD intervention, a multicomponent intervention with carer sleep hygiene education, has best evidence for psychosocial management.

Psychotic symptoms: Psychosocial interventions initially unless symptoms are causing significant agitation, distress or safety concerns. Multifaceted care programme (Gentle Care), which builds a 'prosthesis of care' based on support to compensate for cognitive and functional losses, provides the best evidence.

Vocally disruptive behaviour: Possible causes include discomfort, operant conditioning (due to increased attention), and reduced stress threshold. Therapeutic recreation provides the best evidence.

Wandering: Crucial task is to understand what the wandering means for the person, although this can be difficult to determine. Some evidence for cost-effective and simple to implement psychosocial interventions – for the environmental, sensory, and touch therapies categories.

