Because we're human too

Why dementia training for care workers matters, and how to deliver it.

Alzheimer's Society

Together we are help & hope for everyone living with dementia

November 2024

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Foreword

Getting social care right for people with dementia in England, Wales and Northern Ireland is vital. There are currently around one million people living with dementia in the UK today, a figure that's set to rise to 1.4 million by 2040.[1] Social care can be a lifeline for people with dementia, and helps people manage symptoms and live as well as possible at each stage of the condition. Yet as Executive Director of Dementia Support and Partnerships at Alzheimer's Society, too often I hear from people who are not getting the quality of social care support they need. It can be hard at times to find hope when national headlines talk about social care in crisis. There are some exciting proposals for social care reform being discussed or under way across the three nations, which promise change. But achieving this change can seem a long way off. Yet I am hopeful. Because, while long-term thinking and wider reform is certainly needed, there are also smaller changes that can deliver real benefits here and now.

This is why I'm so pleased we are publishing a report which demonstrates the significant benefits that dementia training for the care workforce can bring to people's lives, and to our wider health and care system. It shows that high quality training could be delivered nationally at relatively low cost.

For people with dementia, well-trained social care staff means improvements in their day-to-day quality of life – and best practice examples of training have been shown to reduce use of antipsychotic medication and physical restraints. For care staff, being trained in dementia can lead to increased confidence and job satisfaction – and could potentially help address an urgent national imperative, namely reducing staff turnover. For care providers, benefits can include increased staff engagement and enhanced reputations with regulators and local commissioners. And for our wider health and care system, there can be significant savings: one long-running study of a dementia training intervention showed savings of £2,000 per care home, per year, to the wider health system (made through reductions in use of primary and hospital healthcare).

Of course, to be effective dementia training for care staff must be good quality. We know that there is much good practice already and our report highlights two examples of this. But sadly, we also know this is not consistent nationally. The quality of training design is vital to its success, as is how well it is facilitated. What's also important are organisational and systemic factors that enable a positive learning environment, such as supportive management and time for staff to reflect. This report reviews the available evidence and distils it into five key components for implementing impactful dementia training in care homes and homecare agencies. Local authorities and care providers have an important role to play, and we set out actions they can take now to improve quality and uptake of dementia training.

The benefits are so significant, and the costs so affordable, that we argue dementia training for care workers should be mandated nationally in England, Wales and Northern Ireland. Key players agree with us: the Adult Social Care Sector Workforce Strategy published in England by Skills for Care in July of this year recommended that all care workers should have dementia training mapped to the Dementia Training Standards Framework. Our vision at Alzheimer's Society is for people living with dementia to be able to easily access affordable, high quality social care that can respond to their dementia-specific and individual needs, delivered by a well-trained workforce. I urge governments, local systems and care providers in England, Wales and Northern Ireland to implement the recommendations in our report and take a significant step towards realising this vision.

Dara de Burca
Executive Director of Dementia Support and Partnerships

13 November 2024

Executive Summary

There are currently 982,000 people with dementia in the UK.[1] Many people living with dementia rely on social care, making up around 60% of people who draw on care at home in the UK,[2] and 70% of residents of older age residential care in England.[3] Yet currently, no legal requirement exists for care staff to undertake dementia training in either England, Wales or Northern Ireland. Whilst some positive steps to upskill the care workforce are taking place across the three nations, developments to date have failed to make dementia training for care staff the priority it needs to be.

As a result, in England, only 29% of care staff undertake any kind of dementia training,[4] while in Wales and Northern Ireland, there is no comprehensive national data available on levels of dementia training amongst care staff. People with dementia and their carers report care that is not personalised,[5] with less than half (44%) of individuals surveyed in England rating care staff's understanding of dementia positively.[6]

This report demonstrates the significant benefits of dementia training to people living with dementia, care staff, care providers and the wider health and care system – showing that it can considerably improve people's quality of life, increase staff job satisfaction and lead to savings in the wider health and care system.

Benefits of dementia training

People living with dementia and their family	Staff	Care providers	Wider system
Receiving care from staff who can understand the evolving needs associated with dementia. Providing a healthier and more ethical means of supporting complex needs such as agitation. Reducing inappropriate prescribing of antipsychotic medications and other psychotropic medications. Promoting better quality relationships. Enabling culturally competent care.	Improved attitudes towards dementia. Improved knowledge and confidence. Higher levels of job satisfaction. Reduced workforce turnover. Potential to reduce stress and burnout.	Improved staff team engagement. Increased activity and engagement between staff and people living with dementia. Improved relationships with family. Enhanced reputation with regulators and local commissioners. Improved physical environment.	Fewer GP visits. Fewer hospital visits.

Based on this evidence, we call on national governments to ensure all care staff undertake dementia training. We also make recommendations to local authorities and care providers on steps they can take now to improve quality and uptake of dementia training. We draw on two best practice examples to show how this can be done impactfully at a relatively low cost, demonstrating that a small investment in high-quality dementia training could deliver significant wider system benefits. By way of example, one long-running dementia training trial demonstrated cost savings of £2000 to the wider health system per care home, per year (made through reductions in the need for primary, hospital, emergency and community health care).

Vital to the impact of dementia training for care staff is the quality of the training. We have reviewed the available evidence on what makes for impactful dementia training and distilled this into five key components, as set out in the table on the next page.

Key components for the implementation of impactful dementia training

1. Evidence informed training design

- Training design should be underpinned by evidence and represent the full diversity of lived experience of people living with dementia, unpaid carers and staff. Providers can assess the quality of dementia training using the DeTDAT tool (Dementia Training Design and Delivery Audit Tool).
- Providers should develop or access appropriate evaluation tools (for example, feedback surveys).

2. Effective delivery method

- Training should use a combination of delivery methods with a skilled and experienced facilitator, including face-to-face or online group learning to enable reflection. If self-directed or classroom teaching are used, they should be combined with interactive methods and use a skilled and experienced facilitator.

3. Inclusive digital learning

- The digital skills of learners and accessibility of digital learning should be considered. Where appropriate, digital training should be accessible on the learner's own devices to enable flexibility.

4. Support and accessibility

- Live interactive support such as coaching, formal mentoring, supervision and/or peer support are essential to support well-being. Training should be relevant and realistic to the role, experience, English language literacy and skill level of trainees. and consider the cultural backgrounds of staff and their clients.

5. Strong leadership

- Effective leadership is vital to both ensure the impact of dementia training is sustained, and to embed an organisational culture which respects and fosters learning. Dementia champions can support implementation and sustainability of training.

Our report highlights the benefits of high-quality dementia training for care staff and shows how this can be delivered. The case for change is clear. What's needed now is swift action, with both governments and local systems leaders playing a pivotal role in improving dementia training. Our recommendations demonstrate how change can be achieved.

Recommendations

National and local decision-makers, and care providers, must take urgent steps to improve dementia training, and help ensure that people living with dementia consistently receive the care they need and deserve.

1 Training in dementia made mandatory for the social care workforce

- Governments in England, Wales and Northern Ireland should enact a statutory duty for all care providers registered with the relevant regulatory body in each nation (CQC in England, Social Care Inspectorate in Wales and Regulation and Quality Improvement Authority in Northern Ireland) to ensure their care staff undertake dementia training. Training content must be mapped to the relevant national framework in each nation (the **Dementia Training Standards Framework** in England, the **Good Work Framework** in Wales and the **Dementia Learning and Development Framework** in Northern Ireland).
- This should be underpinned by sufficient funding, following the precedent in England of the Oliver McGowan Mandatory Training on learning disabilities and autism.[7]

2 Implementation of dementia-specific contractual and commissioning provisions

- When commissioning adult social care services, local authorities in England and Wales, and Health and Social Care Trusts in Northern Ireland, should include a contractual provision obliging care providers to ensure care staff undertake dementia training mapped to the relevant national framework in each nation.

3 Implementation of evidence informed dementia training

- When sourcing and implementing training, local authorities in England and Wales, Health and Social Care Trusts in Northern Ireland, and care providers should ensure all five key components for impactful dementia training, set out in section 7 below, are factored in (in addition to ensuring training content maps to the relevant national framework).

1. Introduction

There are currently around one million people with dementia in the UK, a figure projected to rise to 1.4 million by 2040.[8] Dementia is not an inevitable part of ageing. It is caused by diseases, such as Alzheimer's, that damage nerve cells within the brain. It is progressive, and currently without a cure. There are many different diseases that can affect the brain, and they do so in multitude ways, meaning the symptoms people with dementia experience can vary. People living with dementia draw on social care for support with daily activities, to help them manage their symptoms and live as well as they can.

There are a number of specialist support needs associated with dementia, and in order for social care to best support those needs, care staff need appropriate training in dementia. People living with dementia make up a large proportion of those who draw on care, yet there is no requirement for care staff to undertake dementia training in England, Wales or Northern Ireland. In England, only 29% of care staff undertake any kind of dementia training,[9] while in Wales and Northern Ireland, there is no comprehensive national data available on levels of dementia training amongst care staff. Whilst we do hear of examples of good practice in dementia training, research suggests that much of the training currently provided is not evidenced based or of high quality.[10,11] This is particularly concerning given that, as this report demonstrates, when high quality dementia training is implemented, it can lead to significant benefits for people who draw on care, for care staff and for the wider health and care system. Not only does dementia training deliver these benefits, but it can also positively impact on an urgent imperative in each nation, namely reducing care workforce turnover. Skills for Care data in England shows that social care staff who receive regular training (not dementia specific) in their role have a lower turnover rate (31.6%) than those who do not (40.6%), with learning and development being one of the top three retention factors.[12]

People living with dementia make up a large proportion of those who draw on care, yet there is no requirement for care staff to undertake dementia training in England, Wales or Northern Ireland.

We acknowledge that other workforce factors, such as pay and career advancement opportunities, play an important role in attracting high-quality staff and retaining them once trained. These factors are outside the scope of this report. It is also clear that healthcare as well as social care is vital to the welfare of people living with dementia. Providing high-quality care and support to people living with dementia is a shared responsibility, spanning both the health and care systems; whole system change is needed to improve the care for people living with dementia. But implementing high-quality dementia training for the care workforce is an action that can be taken right now, and it is a vital and relatively low-cost step to achieve significant improvements to people's care.

This report focuses on dementia training for the social care workforce and should be considered against the backdrop of developments in the social care landscape across England, Wales and Northern Ireland. These developments demonstrate that the importance of high-quality training for the care workforce is beginning to be more widely understood.

For example, in England, the recently published **adult social care workforce strategy**, led by Skills for Care, highlighted training as one of the key retention factors that reduced staff turnover and recommended that all care staff should undertake dementia training mapped to the **Dementia Training Standards Framework**. In Wales the new **Social Care Workforce Delivery Plan 2024-2027** noted that "80% of the workforce are keen to improve their skills and knowledge." In Northern Ireland, an Education and Training Workstream has recently been established as part of the Department of Health led Regional Dementia Project Board.

It should also be acknowledged that there are undoubtedly areas of best practice within dementia training: indeed, our report looks in detail at two best practice case studies.

However, all three nations have much further to go. Alzheimer's Society are calling on governments in England, Wales and Northern Ireland to enact a statutory duty for all care providers registered with the relevant regulatory body in each nation[13] to ensure their care staff undertake dementia training, with content mapped to the relevant national framework in each nation.[14] This should follow the precedent in England of the Oliver McGowan Mandatory Training on Learning Disabilities and Autism.[15] But local adult social care commissioners do not need to wait for such a duty to take steps to improve both quality and uptake of dementia training.

Alzheimer's Society is calling on governments in England, Wales and Northern Ireland to introduce a statutory duty for all care providers to ensure care staff undertake dementia training.

When commissioning adult social care, local authorities in England and Wales, and Health and Social Care Trusts in Northern Ireland, should ensure that a contractual provision is included, obliging care providers to ensure care staff undertake high-quality dementia training, mapped to the relevant national framework.

To support our policy calls, we want to ensure that both national and local decision-makers understand what delivery of high-quality training looks like in practice. We have examined the evidence on what impactful dementia training looks like both for staff providing care in people's homes (homecare staff) and care staff working in residential and nursing homes (long-term care staff). We also looked at organisational and other factors that contribute to the success or otherwise of training. Our report draws on this evidence to set out clear, achievable principles for how high-quality dementia training can be delivered. Our message to local authorities and care providers is that when sourcing and implementing training, they should ensure these core components (set out in section 7 below) are factored in.

Throughout the report, we draw on relevant expertise, including insights from people living with dementia and their carers, leading academics in the field and practitioners in the sector.

The case for change is clear. We know the benefits of dementia training for care staff, the key principles for impactful training and we understand the enablers and barriers to successful implementation. What's needed now is action.

2. Social care and dementia

People living with dementia make up around 60% of people who draw on care at home in the UK[16] and 70% of residents of older age residential care in England.[17] They deserve high-quality social care that meets the specific needs associated with dementia, so they can live as well as possible at each stage of their condition.

People with dementia

70%

of residents of older age residential care in England.

60%

of people who draw on care at home in the UK.

Skills gap

29%

of care staff in England are recorded as having had training in dementia in 2023/2024

65%

When asked what would best help to improve the lives of people living with dementia, **65% of people said more care workers skilled in caring for those with dementia**[25]

Less than four in 10 are satisfied with the support available for people living with dementia

In 2022, the All-Party Parliamentary Group (APPG) on Dementia (a cross-party group made up of MPs and Peers with an interest in dementia) conducted an inquiry into what people with dementia want and need from social care, and they identified a number of specific needs associated with the condition:[18]

Communication

Dementia can have a profound effect on an individual's communication, and communication challenges often increase as the condition progresses. Care staff need to both communicate effectively and be able to support effective communication.

Complex needs, including behaviours that challenge

Staff may struggle to understand people with dementia as they try to communicate a response to environmental stimuli (including provision of care) or an unmet need that is causing them distress or pain. As a result, staff may inappropriately use restrictions or restraints to manage behaviour experienced as agitation and aggression, both physical and verbal. Care staff need to understand why such behaviour may arise, how to address the underlying causes of such behaviour, and be able to demonstrate the empathy and patience required in such situations.

Cognitively stimulating activity

Activities that are cognitively stimulating can help to preserve existing cognitive and functional abilities and delay progression of decline,[19,20] as well as improve wellbeing, bringing the individual joy in their daily life. In this context it is vital to understand people's individual interests – activities that are engaging for one person (for example, gardening) may not be for another person with different interests.

Needs associated with different types of dementia

There are a number of different diseases that cause dementia, which can result in differing symptoms. It is important that care staff understand how symptoms may differ and how to support individuals' varying dementia types.

The 2022 APPG report found that people living with dementia and their carers want care staff with the knowledge and understanding to meet these needs, and to deliver personalised care.[21]

They also want staff with the right skills to provide culturally appropriate care, as well as staff that understand the importance of involving family members as partners in care.[22] But research shows this is not currently consistently being delivered. The APPG inquiry revealed that less than half (44%) of individuals living with dementia in England surveyed rated care staff's understanding of dementia positively, while two in five reported their care was not personalised.[23] This is not surprising given that only 29% of care staff in England are recorded as having had training in dementia in 2023/2024,[24] with the data failing to provide information on the level of dementia training staff received, neither the duration or the quality.

A recent survey commissioned by Alzheimer's Society suggests that the situation in England has not improved since the APPG report in 2022 and suggests similar challenges in Northern Ireland and Wales. The survey gathered responses from 3,476 people, across England, Wales and Northern Ireland, who are close to someone with dementia or living with symptoms, and found that:

- less than four in 10 are satisfied with the support available for people living with dementia; and
- when asked what would best help to improve the lives of people living with dementia, 65% of people said more care workers who are skilled in caring for those with dementia.[25]

3. State of play in England, Wales and Northern Ireland

Despite the clear need for – and benefits of – dementia training, it is not yet mandatory for care staff in either England, Wales or Northern Ireland.

England

The '**Dementia Training Standards Framework**' (DTSF) (developed by Health Education England and Skills for Care, published in 2015 and updated in 2018) describes the skills and knowledge needed by the care workforce in supporting someone living with dementia. It is structured in tiers applicable to different levels of roles and responsibilities of staff, and is applicable across health and social care, although not mandatory.

In England, there is no formal registration process for social care workers, although Skills for Care guidance sets out the statutory and mandatory training that staff must undertake as part of their induction process.[26] Dementia is not listed as mandatory, although since July 2024, it has been listed as an example of additional training that could be undertaken based on the needs of the service and people who draw on care and support.[27] NICE Dementia Guidelines[28] recommend that: "Care and support providers should provide all staff with training in person-centred and outcome-focused care for people living with dementia." Additionally, regulation 18 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 requires CQC-registered providers to ensure staff receive such appropriate support, training, professional development, supervision and appraisal as is necessary to enable them to carry out their duties.[29]

Wales

The '**Dementia learning and development framework for Wales**' (the 'Good Work Framework'), published in 2016, sets out a rights-based, wellbeing and person-centred approach to dementia education, and identifies skills and knowledge for three different tiers of workers ('Informed, Skilled and Influencer'). These tiers are not mapped to levels of roles and responsibilities, rather the framework suggests a 'complementary model of expertise' where everyone involved in the care of someone living with dementia has something to contribute. Despite the Framework being available to support training, a 2023 Social Care Wales survey[30] identified that 40% of care staff felt there were barriers to accessing training at work.

All adult care home workers and domiciliary care workers in Wales are required to be registered with the national regulatory body, Social Care Wales. Two registration routes exist: 1) register with a qualification, and 2) register by employee assessment.

If registering via route 1, the Learning Outcomes and Delivery guidance from the Level 2 Health and Social Care qualification in Wales does include dementia-specific outcomes.

If registering via route 2, the employer must assess the employee's understanding of certain criteria (which do not reference dementia), and a carer does not have to complete their level 2 qualification for up to six years into their post (although Social Care Wales expects most to complete theirs within three years).[31] The employer assessment form for route 2 does state that employers are expected to support employees to complete the **All Wales Induction Framework** (AWIF).

The AWIF includes a number of dementia learning outcomes, including: 'how person-centred approaches can be used to support individuals living with dementia' and 'what needs to be considered when communicating with an individual with dementia.'[32] However, it is not clear how or if completion of the AWIF is monitored.[33] There is no specific national data available on levels of dementia training among care staff. The Social Care **Wales Workforce Delivery Plan** 24-27 states: "75 per cent of care workers hold the qualifications needed to work in the sector, 22% are working towards the required qualifications and 4% are working through an apprenticeship." However, we have been unable to obtain a breakdown of what 'qualifications needed to work in the sector' refers to.

Northern Ireland

The '**Dementia Learning and development framework**' (published in 2016) outlines the knowledge and skills that health and social care staff require in order to respond sensitively to the needs of people living with a dementia, their families and carers. It is structured under four incremental tiers, applicable to different roles and responsibilities of staff. The Framework is applicable to employers and educational organisations who provide education and training to health and social care staff and students.

As in Wales, the care workforce in Northern Ireland is required to register with the regulatory body, the Northern Ireland Social Care Council (NISCC). There is currently no training required to register, but staff should receive suitable induction training from their employer within the first six months of employment. NISCC have an **induction programme document**, but this does not reference dementia or dementia training. There is no national data available on levels of dementia training among care staff.

Recent developments

There have been positive steps taken recently in each nation towards improving training and career progression pathways for the care workforce. However, to date these developments have failed to make dementia training for care staff the priority it needs to be.

England

In January 2024, the Conservative Government introduced the Care Workforce Pathway, which sets out a national career structure for the care workforce. This aims to improve perceptions and experiences of a career in care – to improve attraction and retention of staff. The Pathway includes a new Level 2 Care Certificate, which includes a dementia component, with the guidance suggesting that staff providing direct care to people with dementia should have dementia training, referencing the Dementia Training Standards Framework as a suggested learning resource. However, as with the existing Level 2 certificate, the new certificate is not mandatory and is therefore at the discretion of employers as to whether they enrol employees.

Encouragingly, a new sector-supported Adult Social Care Workforce Strategy, led by Skills for Care, published in July 2024, recommends that all care staff should undertake dementia training mapped to the DTSF.[34] The Labour manifesto promised a Fair Pay Agreement for care staff, to "set fair pay, terms and conditions, along with training standards."[35] In September 2024, the new Labour Government published an Employment Rights Bill, which will give the Secretary of State powers to establish an Adult Social Care Negotiating Body, and has confirmed that consultation will be undertaken on how the Fair Pay Agreement will be designed."[35] Alzheimer's Society believe that the Fair Pay Agreement represents an opportunity to link pay to skills, including a requirement for all staff to undertake dementia training.

Wales

In May 2023, the Welsh Government published a draft proposal for a Pay and Progression Framework[36] for the social care workforce. It sets out a series of bands for different job roles and includes the skills, values, knowledge, understanding and typical tasks for each one. It sets out that new joiners should complete the All-Wales Induction Framework and then work towards Level 2 Health and Social Care (which does include dementia learning). In 2020, the Welsh Government published a **Workforce Strategy for Health and Social Care**, committing to "investment in education and learning for health and social care professionals" to "deliver the skills and capabilities needed to meet the future needs of people in Wales." Further detail was provided with the **Social Care Workforce Delivery Plan** 23-27 published in June 24, which noted that "80 per cent of the workforce are keen to improve their skills and knowledge", and committed to "clear education and training pathways that are attractive and accessible." Neither document makes specific mention of dementia training.

Northern Ireland

The Northern Ireland Social Care Council have been commissioned by the Department for Health (DoH) to develop:

- a continuous professional learning framework, career development pathway
- qualification-based register for social care workers.

A new practice framework is under development to support social care workers to develop professionally, and all new social care workers will be required from September 2024 to obtain a new work-based entrance qualification – the Safe and Effective Care Practice Certificate. This new entrance qualification will cover the mandatory training people would be expected to undertake, such as moving and handling, understanding of medication and first aid. Currently available information[37] regarding the new Certificate suggests that dementia will not be included as part of this mandatory training.

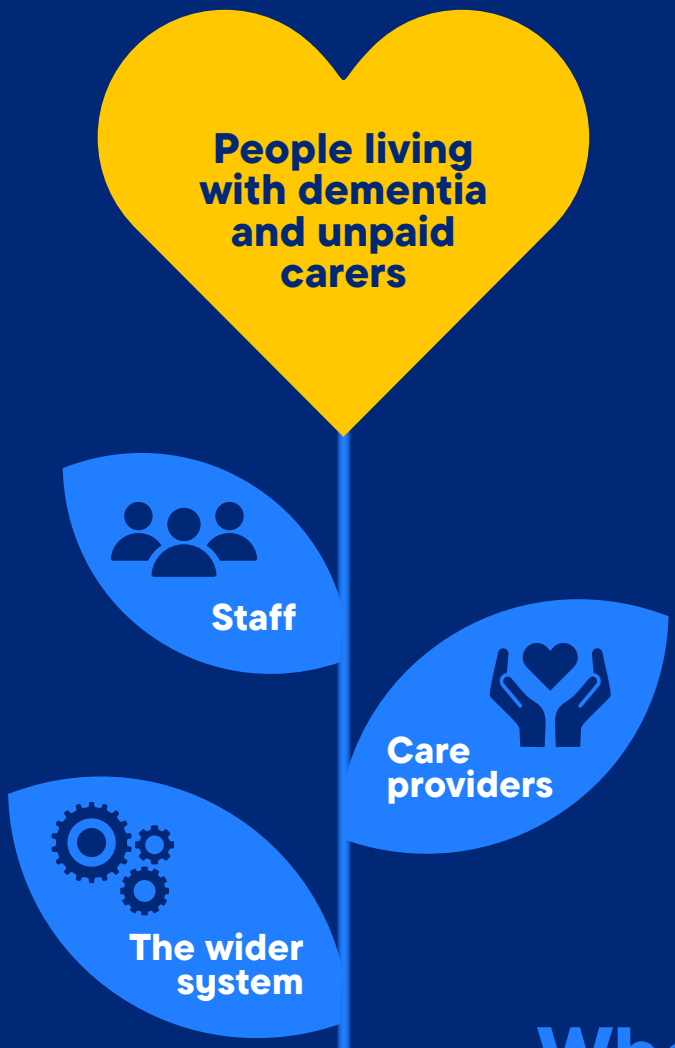
The Social Care Collaborative Forum (SCCF), who were tasked by the DoH to deliver adult social care reform, has established a workstream focused on Workforce Development, which is developing a workforce strategy. Additionally, an Education and Training workstream has been set up as part of the Regional Dementia Project Board (RDPB). The RDPB was established by the Strategic Planning and Performance Group (SPPG), who are accountable to the Department of Health. Encouragingly, the long-term aim of this workstream is to achieve mandatory dementia training for the workforce.

Why mandatory training is needed

- **Current guidance on dementia training is not working. For example, in England, Care Quality Commission Regulation 18(2)[38] and NICE's guidance[39] stipulate that care staff should have appropriate training to deliver quality care. Yet most care staff have not received any form of dementia training.[40]**
- **High turnover rates within the social care workforce[41] (and particularly high turnover rates within the first three months of people starting their role)[42] mean that if dementia training is not mandated, and so not completed at the outset of a care worker's employment, a large proportion of the workforce will remain untrained.**

4. Benefits of quality dementia training

High-quality, evidence-informed dementia training and education delivered to care staff can lead to positive impacts for people living with dementia and staff delivering care. It can also benefit the wider system by reducing hospital admissions or additional healthcare usage.



Who benefits from dementia training?

4.1. Benefits to people living with dementia and unpaid carers

Helps staff to understand the evolving needs of the person living with dementia

People with dementia require more support as their dementia progresses and they, and their unpaid carers (including family members), want reassurance that their needs will be met. People with dementia are likely to experience additional behavioural and psychological symptoms that can manifest as behaviours that challenge. Behaviours that challenge (also sometimes called behaviours that communicate),[43] can include expressions of aggression or restlessness, all of which indicate unmet needs requiring greater care and support.

These expressions are common amongst people living with dementia in the community (60%),[44] and more so in care homes, with some studies citing symptoms in over 70% of residents with dementia.[45] Training and education for care staff that enable them to understand and best meet those needs, is crucial in reducing these symptoms and delivering good quality person-centred care.[46] Evidence highlights that high-quality training improves staff's ability to understand and manage these needs and improves the quality of life for people living with these symptoms.[47]

Provides a healthier and more ethical means of supporting the management of agitation

For some people with dementia, agitation might be a symptom of their dementia and for others it might be a behavioural response to feeling frightened, confused or angry if care and care environments do not meet their needs. Agitation, especially involving physical or verbal aggression, is frequently the most challenging aspect of dementia for care home staff to experience.[48]

Training care staff in person-centred approaches to understand how to prevent and manage stress and distress is particularly important for people with dementia and their family members. This is partly because older adults with dementia are at a higher risk than other people of experiencing the use of restriction and restraints to help manage agitation, despite the numerous negative physical and psychological outcomes associated with restraint use. One of the most common risks associated with using restraints is physical injury or immobility. When used in long-term care settings, prolonged use of restraints can lead to falls, dehydration, skin breakdowns, circulatory problems, infections and even death in certain cases. Restraints may also lead to the person with dementia becoming more confused or agitated due to a loss of freedom. This can cause feelings of helplessness and vulnerability, as well as an increased risk of developing psychosis-like symptoms, such as delusions or delirium. Agitation is therefore associated with lower quality of life for care home residents[49] as well as increased costs, and work-related stress in care home staff.[50] Person-centred care staff dementia education programs are available that are effective in reducing agitation and the number of restraints[52] amongst long-term care residents.

> **Training is so important as we [people living with dementia] too are human beings.**
>
> M, person living with dementia

Reduces inappropriate prescribing of antipsychotic and other psychotropic medications

Psychotropics are medicines that affect behaviour and mood, and include a variety of medicines such as antipsychotics, antidepressants, benzodiazepines, and hypnotics. Quality dementia training that focuses on person-centred care has shown strong positive results in reducing the use of anti-psychotic medication and other psychotropic medicines in care homes. This is important because whilst there is modest evidence of some clinical benefits of psychotropic medication use in dementia, there are also considerable risks. These include worsening of cognitive decline, increased risk of stroke, falls, fractures[53], and an increased risk of death.[54] Tackling inappropriate use of psychotropic medications for the management of dementia symptoms through training is therefore essential as it maintains quality of life.

Promotes better quality relationships between the person living with dementia and staff

Research also highlights the importance of the quality of one-to-one relationships between staff delivering care and people living with dementia and their unpaid carers. For example, one qualitative study[55] collecting insights from older people with dementia and their family carers, found that where homecare workers had a deep understanding of the lived experience of dementia and the tools and skills to develop effective communication and rapport, more positive experiences of receiving care were expressed. Many participants in this study described the positive effects of being able to establish an effective relationship with home care workers and the importance of mutual collaboration to best meet the needs of the person with dementia. Building and maintaining relationships is essential to adhering to the partnership working theme of the Care Act (2014).

> **Cultural specificity is a really important issue.**
>
> HM, person living with dementia

Enables culturally competent care

Dementia does not discriminate – it affects people of all cultures and backgrounds from diagnosis to end of life. Research highlights that people with dementia who come from culturally and linguistically diverse backgrounds often face poor health and social outcomes such as stigma, depression, and reduced help seeking behaviours.[56] The Alzheimer's Society Health and Social Care committee, made up of people with lived experience of dementia, highlighted the importance of quality dementia training in enabling culturally competent care. Training should enable care professionals to meet the social and cultural needs of the person with dementia, and this is essential whatever the care professional's cultural background and preferences.

Homecare workers' understanding of their clients' identity can enable active participation in tasks and meaningful choice.[57] The Care Quality Commission (2023)[58] found that good quality, culturally competent, dementia training can counter a lack of awareness of specific needs and preferences. For example, an individual's service engagement may be interlinked with their culture, faith, ethnicity, gender, sexuality, disability and previous experiences, and it is important for care workers to be sensitive to these. Training staff to be more aware and deeply understand structural inequalities can enable them to be more proactive in addressing issues of inequality in care planning and delivery.

Social care is provided by a culturally diverse workforce.[59] Research highlights the importance of training for migrant care workers that includes support with communication. More research on whether training should also cover care workers' own cultural beliefs, values and attitudes towards dementia is needed, as there is currently a lack of clarity regarding the intersection of culture in the provision of person-centred dementia care. Care workers from diverse backgrounds may benefit from training to support cross-cultural interactions.

Equality, diversity and inclusion are referenced in the training standards for England, Wales and Northern Ireland and in NICE guidance.[60]

> **I think, if [training] is done right, it'll be a much better experience for people living with dementia.**
>
> R, person living with dementia

> **Training [can] enable people to have a different perspective of dementia and to ensure dementia gets the respect it deserves. Currently neither people living with dementia, nor their carers get that respect.**
>
> M, person living with dementia

4.2. Benefits to staff

International studies reveal that care staff have low confidence in their ability to deliver quality care, lack dementia-specific knowledge and feel unable to support the complex care and communication needs of people with dementia. This includes the management of certain dementia-specific issues such as physical and verbal aggression, which can be caused by distress and needs not being met. They also feel inadequately skilled when they communicate with people with dementia, which may contribute to lower job satisfaction.[61] Quality dementia training can increase staff competency and attitudes towards dementia along with the actual care of people with dementia.[62]

Improves attitudes, knowledge and confidence in ability to support people with dementia

Long-term care workers who complete training can experience improvements in their knowledge of dementia and their confidence and belief in their ability to express caring behavior and build compassionate relationships with people with dementia.[63] When coupled with appropriate organisational support, this can lead to increased levels of activity, improved communication, less task-focused care and increased resident well-being.[64] In addition to this, staff attitudes towards dementia have been found to be positively influenced by dementia education,[65] with changes maintained over time.[66]

Has the potential to reduces stress and burn out

For homecare workers, there is some evidence that well-designed dementia training can support staff confidence and reduce the likelihood of experiencing stress and burnout.[67]

However, as with all other benefits mentioned, it is important to note that research also highlights a range of other factors that can influence staff feelings of confidence and competence to deliver dementia care. These include organisational climate, the provision of practical support to implement both training and care practices, promotion of staff autonomy and trust. These in turn may impact individual factors, such as staff burnout and staff attitudes. More positive attitude and intentions to implement person-centred care can lead to greater confidence.[68] Experts emphasise the importance of care worker well-being as an important factor in provision of good dementia care.

Enables higher levels of job satisfaction

Delivery of dementia training to care staff can also help foster higher levels of job satisfaction and career commitment amongst staff.[69] For staff to experience these benefits of dementia education and training, other factors beyond the training itself are just as important. We explore these factors further in section 5.

4.3. Benefits to care providers

Qualitative findings from research projects such as FITS into practice[70] and WHELD[71] highlight positive changes in care homes who have completed training. These include improved physical environment, improved staff team engagement, increased activity and engagement between staff and residents, improved relationships with family and enhanced reputation with regulators and local commissioners.[72]

4.4. Benefits to the wider system

There is emerging research that high-quality dementia training can also to lead to wider system benefits. Dementia has a significant impact on healthcare services.[73] One in six hospital beds today are occupied by people with a diagnosis of dementia. Compared to people without dementia, people with a diagnosis visit the GP up to three times more per year. Without action, and as prevalence increases, this impact is likely to grow: by 2040, there will be 6.9 million additional primary care contacts associated with dementia, requiring an estimated 1.7 million more hours of primary care time.[74]

However, through improved dementia training for the workforce, positive progress can be made. The WHELD training intervention in care homes, described in more detail in section 5, led to fewer emergency hospital admissions and fewer GP visits. We project that if WHELD were to be rolled out nationally, this might also lead to significant cost savings to the wider system.

More research is needed to quantify the system benefits of quality dementia training.

5. Case studies of best practice dementia training for the social care workforce

Guided by our own research and a recent evidence and policy review by the NIHR Dementia and Neurodegeneration Policy Research Unit (Queen Mary),[75] we have identified two recent evidence-based dementia training and education programs trialled in the UK. These programs have been found impactful, simple to use by social care staff and for people living with dementia to receive: WHELD (Well-being and Health for People Living with Dementia) and NIDUS-Professional (NIDUS stands for 'New interventions for Independence in Dementia').

Many high performing care organisations currently implement effective dementia training, that are not WHELD or NIDUS-Professional but are grounded in evidence. One example is FITS into practice,[76] a pre-cursor of WHELD that was built on extensive stakeholder and patient and public involvement co-creation. In our report we use WHELD and NIDUS-Professional as costed case study examples to highlight what may be achievable if modest investments were made to implement evidence-based training to support the dementia care workforce.

5.1. WHELD

WHELD is an optimisation of FITS into practice and is an evidence-based person-centred training programme for care home staff supporting people with dementia. Shown to be effective in two large clinical trials, WHELD seeks to reduce reliance on antipsychotic medication and uses social interaction, personalised activities and exercise to improve care. In response to the Covid-19 pandemic, WHELD was adapted to online delivery to create iWHELD, to ensure care homes continued to have access to high-quality evidence-based dementia training.

iWHELD consists of 12 online coaching sessions across four months with an iWHELD coach. Weekly for the first eight weeks, then fortnightly for the remaining eight weeks. Care homes also have access to an online digital hub of ideas and resources and peer-to-peer support with a wider community of care workers. Within each participating care home, between two and four existing staff are self-appointed as Dementia Champions to support the implementation and evaluation of iWHELD to the rest of the care home.

Within the hub and throughout the coaching, tools and exercises offered through WHELD and iWHELD focus on five topics:

1. **Person-centred care**
2. **Creating moments that matter**
3. **Personalised care planning**
4. **Understanding unmet needs**
5. **Reviewing and reducing antipsychotic medication**

Both remote[77] and in-person[78] iterations of the WHELD intervention have demonstrated effectiveness in improving quality of life (QoL) for individuals with dementia, reducing antipsychotic medication use, and agitation and aggression amongst residents. Early findings also indicate the benefits of WHELD in improving staff attitudes towards people with dementia, as well as improved job satisfaction.

Alongside this, residents experience improvement in quality of care, with fewer emergency hospital admissions and fewer GP visits. The benefits were greatest in people with moderately severe dementia.

Both WHELD and iWHELD have been successfully implemented in over 1000 care homes and with over 1600 residents. iWHELD coaches reported seeing changes in the communication skills of staff facilitating activities, including being able to involve people living with advanced dementia with loss of verbal skills. Coaches also reported positive feedback from care home managers and relatives.[79]

iWHELD Costings

We estimate that the total cost of delivering the iWHELD intervention to all 14,705 CQC-registered care homes in England would be approximately £29.4m per annum. This includes the fixed cost of the digital platform, coach/trainer fees to deliver the training and provide mentorship, and quality oversight measures, including a management structure. Our costings methodology is set out in Appendix 2.

5.2. NIDUS-Professional

NIDUS-Professional is a training and support intervention for home care workers caring for people living with dementia in their own homes. The program comprises six online sessions, lasting from an hour to an hour-and-a-half, delivered by two facilitators to groups of between six and eight home care workers (HCWs). Sessions are delivered over three months and are followed up by three monthly catch-up groups to support care workers in applying their learning in practice. During the six sessions, facilitators use an evidence-based manual to cover four key topics:

1. **Building positive relationships and managing reluctance to engage.**
2. **Supporting people to stay active and involved in meaningful activities.**
3. **Supporting each other, and working as a team with carers and other professionals.**
4. **Managing behaviours that challenge.**[80]

NIDUS-Professional is the first dementia training and support intervention to be trialled and tested in UK home care agencies.[81] The findings of the study show that, once engaged, home care workers valued the opportunity to speak with peers, reflect on their practice and learn new strategies. The sessions fostered new connections between home care workers, and increased the number of requests for agency-level peer support.

Home care workers involved in NIDUS-Professional welcomed the training's practical focus and reported applying learning to improve client care, including innovative communication techniques, ideas for enjoyable activities, improved understanding of behaviour and relaxation exercises to alleviate clients' anxieties.[82]

"Not only are we benefiting but primarily our people who we're looking after are benefiting. It is just fabulous, and you can make even more difference to those people and their families with the support that you can offer if we've got some more strategies, like we've learned from talking to each other."
Care professional

Home care workers reported using strategies to promote their own wellbeing and developing new support systems. In addition to this, home care workers also reported increased confidence in their skills. Some home care workers felt empowered to advocate for change including sharing learning with colleagues, asking management to implement improvements to agency systems and care planning processes, establishing peer support groups, and requesting additional dementia training for those unable to receive NIDUS-Professional.

The overall findings contribute to the evidence showing that where home care workers are supported to build skills, confidence and a sense of value in their work through peer support, reflective practice and practical strategies, they are enabled to deliver better quality care.[83]

NIDUS Costings

We estimate that a roll-out of NIDUS-Professional to all 15,000[84] homecare agencies in England registered with the CQC would cost approximately £24 million including staff reimbursement costs. Full details of our costing methodology are set out in Appendix 2.

5.2. Cost benefits of national roll out of high-quality dementia training

Not only would rolling out dementia training for care staff nationally lead to benefits for people with dementia and care staff, but it would also be cost effective for governments.

As set out above, the costings for rolling out iWHELD and NIDUS-Professional nationally are relatively small. Furthermore, after accounting for the cost of implementing the iWHELD programme, health and social care cost savings equated to approximately £2,000 per care home, per year (primarily due to fewer hospital and GP visits).[85] If all CQC registered care homes in England were iWHELD trained, this would equate to approximately £29.4 million national cost savings. Equally, if more homecare staff were well-trained, as they were with NIDUS-Professional, we could potentially keep more people with dementia at home for longer, reducing the time they need to spend in costly residential or nursing care. For example, training staff using the NIDUS-Professional model in one homecare agency costs £1,606, which is less than two weeks of full-time care in a care home.[86]

6. Critical enablers and barriers to success of training implementation

When looking at the implementation of impactful dementia training, it is important to consider readiness for change and approaches to achieving behavioural change at an individual and organisational level.[87] The 'What Works? In dementia education and training' is a key study that helps us to understand critical enablers and barriers to the success of training.[88]

> **I think very key... is how busy the people are in care homes and also people that visit [in your own home]. They're on a time constraint of, you know 15 minutes, if you're lucky, three times day.**
>
> Carer of someone living with dementia and health and social care professional

Having an organisation that understands the importance of training, and supports its employees to feel valued and able to implement their training into practice is key to supporting staff to stay within their organisation. Effective training should understand the individual organisation's wants and needs to support implementation and sustainability of training.

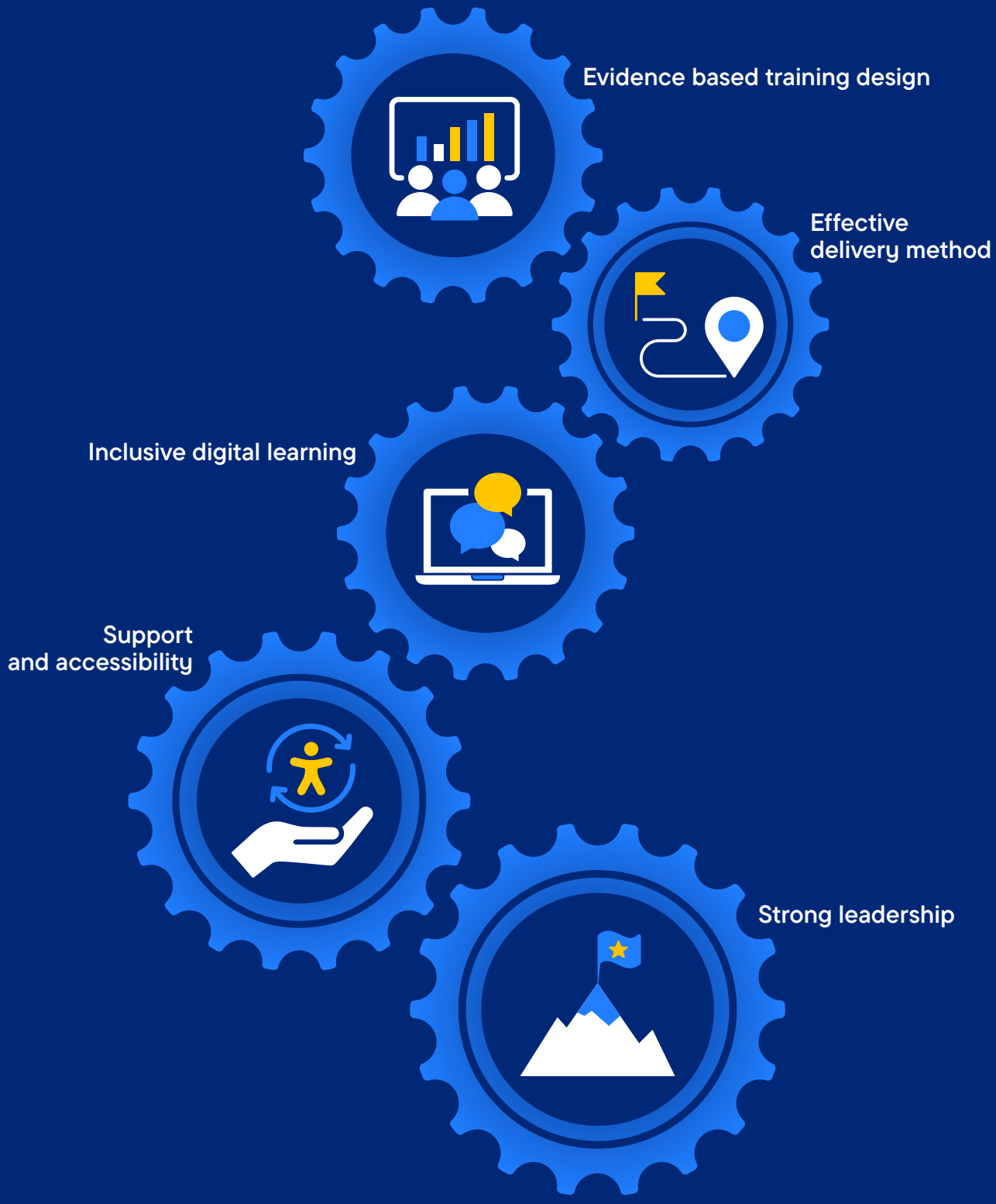
> **[People who undertook training] would try for so long to make the changes, and in the end they would just give up because there wasn't that support.**
>
> Care professional and person living with dementia

Table 1 summarises some of the critical enablers and barriers to the implementation of dementia training identified from published literature. We combine key features of behavioural change frameworks such as the COM-B model[89] which focuses on individual factors that impact on behavioural change and the i-PARHIS[90] and Theoretical Domains[91] Frameworks, which focus more on wider organisational factors.[92] Experts suggest that optimising the system in which staff are working will enhance the benefits and sustainability of training.

Table 1 **Enablers and barriers of dementia training and education**

	Enablers	Barriers
Capability Affecting how staff felt in their ability to implement training into practice including their knowledge, skills, memory, attention and decision-making processes.	Face-to-face learning Group-based learning Adaptable training Multi-disciplinary perspectives Experienced staff	Acceptability Relevance to job role, skill level and experience Training accessibility One-size-fits-all training One-off single delivery Digital skills of staff
Opportunity The ability of staff to attend training and implement training into practice, including staffing, resource and environmental factors.	Designated time for training during paid hours Flexible training Ability to access external training Shared resources Pre-planned staff cover Protected time to reflect	Lack of time Competing demands. Lack of dedicated training space. Difficulties releasing staff to complete training. Lack of time to put training into practice. Poor service user engagement. Location/distance to travel. Costs. Staff turnover. Staffing issues including short staffing and inappropriate staffing ratios Reduced access to speciality staff for support
Motivation The goals, intentions, role, beliefs and emotions of staff including reinforcement.	Skilled, experienced, proactive facilitator Mixed peer group training. Personal values. Incentives to complete training (badge, certificate, monetary). Committed training lead. Committed, proactive staff. Peer support. Formal, trained mentors. Staff feeling valued by their clients, organisation and society.	Having to complete training in own time. Lack of interest in learning. Low staff morale. Burnout. Job satisfaction. Failing to appreciate why training is important. Perceived as a low-status profession. Inappropriate, disengaged mentors.
Organisation The wider context of the organisation setting the training is taking place within, including social and cultural factors.	Positive learning culture which values training. Workforce development strategy in place. Training reinforced by organisational goals. Supportive management who are engaged with the intervention. Effective leadership. Work environment which is supportive of good dementia care. Promotes staff autonomy and trust. Practical support to implement training into practice. Needs-based model of care.	Lack of funding. Challenging work environment. Difficulties evaluating the impact of training. Lack of sustainability of changes due to training. Task-based model of care. Lack of management support.

7. Key components for impactful dementia training



This section articulates five key components for the implementation of impactful dementia training. They have been informed by current available evidence, largely building on knowledge from the 'What Works? In dementia education and training' study and through consultation with experts in the field. We also layered onto this knowledge our understanding of core principles for social care for people living with dementia; and a review of the dementia training standards and guidance in the three nations of England, Northern Ireland and Wales.

These components only apply to the implementation of dementia training, not content. Providers must also ensure that the content of dementia training is mapped to their relevant national framework, namely the Dementia Training Standards Framework in England, the Dementia Learning and Development Framework in Northern Ireland and the Good Work Framework in Wales. Content of dementia training should also be updated regularly to reflect latest research findings and best practice guidance in dementia care.

1. Evidence informed training design

- Training design should be underpinned by evidence and represent the full diversity of lived experience of people with dementia, unpaid carers and staff. This can be achieved by involving them in the creation and/or delivery of training.
- Providers can audit the quality of dementia training design and delivery methods using the DeTDAT tool (Dementia Training Design and Delivery Audit Tool).[93] This tool contains guidance on the minimum time length and other key features of impactful dementia training. Providers should also observe training delivery to ensure adherence to best practice.
- Providers should develop or access appropriate evaluation tools, for example feedback surveys and knowledge and attitudes questionnaires.

"It's essential that people living with dementia are actually involved in the design of the training."
R, Care professional and person living with dementia

2. Effective delivery method

- Training should use a combination of delivery methods with a skilled and experienced facilitator. Self-directed learning (such as a workbook or e-workbook) can be used but should always be combined with live interactive delivery methods such as group discussions (whether face-to-face or online), to enable reflection. This facilitates learning and retention of information.
- Interactive learning methods which reflect real life experiences should be used. If simulation training (such as role play or virtual reality) is used, adequate time should be given for preparation and debriefing to ensure psychological safety of staff.

3. Inclusive digital learning

- The digital skills of learners should be taken into account. For example, if someone has low digital literacy, training in how to use digital platforms should be included at the outset, alongside ongoing support.
- Digital learning should be accessible and where appropriate, available on own devices to support flexibility for a workforce with competing demands on time. This is particularly important for home care workers who often travel as part of role responsibilities and who may work in geographically dispersed settings.
- It is important to consider access to internet when considering digital learning, particularly for those working in rural areas.

4. Support and accessibility

- Live interactive support such as facilitation, coaching, formal mentoring, supervision and/or peer support, either in person or virtual, is essential to support the delivery of training including building confidence of trainees and to facilitate learning. Dementia training and person-centred care can make trainees more emotionally vulnerable, and it is important to recognise emotional and well-being support needs, for example when discussing safeguarding issues and coping with grief.
- Training should be tailored to be relevant and realistic to the role, experience, English language literacy and skill level of the trainees, with local factors and cultural backgrounds of both staff and people living with dementia taken into account. A one-size-fits-all approach to dementia training should be avoided.

5. Strong leadership

- Effective leadership is vital to ensure the long-term impact of dementia training and embed an organisational culture which respects and fosters learning.
- Dementia champions in the context of training are staff with knowledge and skills in the care of people with dementia who are trained to support implementation of training - including through informal learning. They can help identify and nurture the skills and experience of a wide range of staff, thus building further capacity and capability in dementia care. Care must be taken to select dementia champions who are appropriately trained as trainers and are influential within their organisations.

8. Conclusion

Our vision for people living with dementia in England, Wales and Northern Ireland is for everyone to have access to high-quality social care that meets their dementia-specific needs, delivered by a well-trained and supported workforce.

In the current climate, social care reform can appear challenging and sometimes out of reach. Government plans for broad social care reforms and, in England and Wales, promises of a National Care Service, are hopeful but do not engender imminent change.

Whilst working on these wider reforms governments must take action to improve social care for people with dementia now. Our report shows that a relatively small and achievable change – improving quality and uptake of dementia training for the care workforce – could have a significant impact.

Implementing mandatory high-quality dementia training for the care workforce could improve quality of life for people living with dementia, result in higher levels of job satisfaction within the workforce, and reduced pressure on the wider system via a reduction in hospital and GP visits. Our case study examples, WHELD and NIDUS-Professional, show how this can be done, and our costings demonstrate a national roll out is affordable.

In making this change, governments must ensure that everyone with dementia benefits, wherever they draw on social care. Only a statutory duty can achieve this, and national governments in England, Wales and Northern Ireland must take action urgently and introduce this.

Local governments and care providers must also take action now. Pockets of good dementia training practice exist, but it is not consistent or at scale. Local authorities must ensure the care providers they commission have their staff properly trained in dementia, and care providers should use our principles to source high-quality training.

Governments, local leaders and care providers all have a critical role to play in improving social care for people living with dementia. By taking forward the recommendations in this report, and through investment and prioritisation in dementia training, significant progress across England, Wales and Northern Ireland can be achieved resulting in positive and lasting impact for people living with dementia now and in the future.

Appendix 1
Methodology

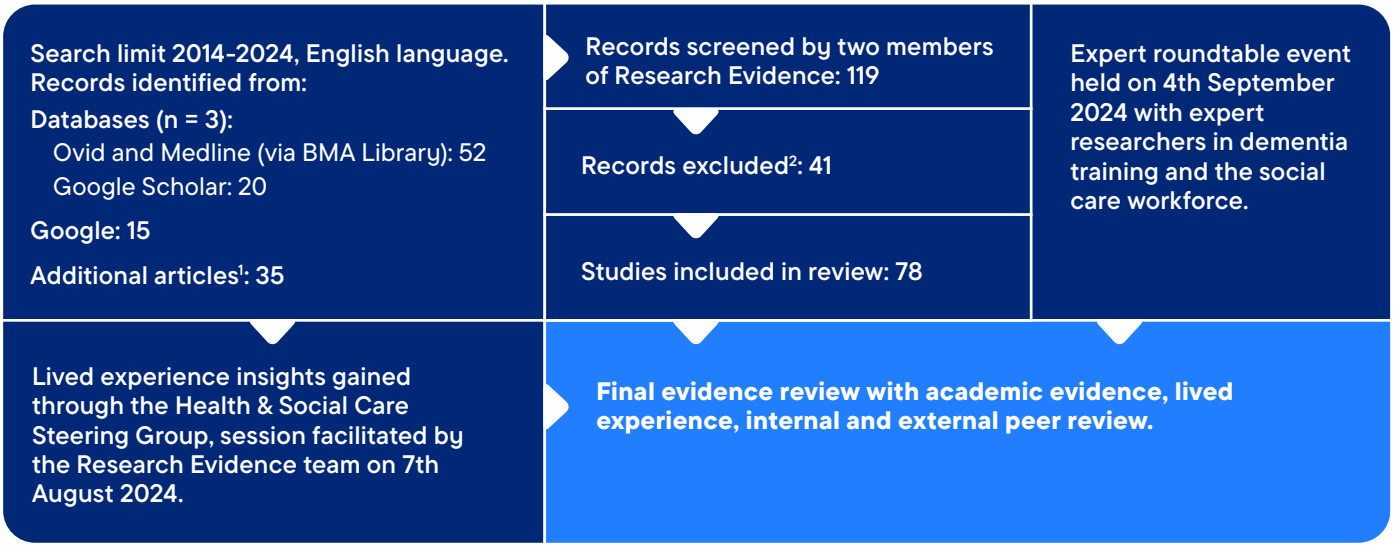
The social care workforce is diverse and there are many different occupations and settings involved in delivering care and support for people living with dementia. Our evidence review focuses on the roles of home care workers and long-term care workers. It does not look at regulated professionals. This is largely due to the two main service settings for social care being residential and domiciliary (home-based) care. In addition, by job role, approximately 76% of posts are direct care workers (people who work directly with service users).[94]

Definitions:

- References to social care in this report refer to adult social care only
- Home care worker also known as domiciliary carers are professionals who provide direct care within residents own homes, such as through assisting with household tasks, medication, and other activities that help to maintain quality of life.
- Long-term care worker are professionals who provide direct care to residents in nursing and/or residential homes, also known as care homes.
- Care workforce encompasses primarily the home care and long-term care worker roles but may also include the wider social care workforce.
- Dementia training - defined as any formal method to enable learning that uses expert input (via a teacher, coach, mentor, trainer or facilitator) to develop people's skills and understanding of dementia and how best to support those living with the condition. It most commonly relates to a specific role and has a focus on application of knowledge into practice.[95]
- Learning - the process of acquiring new understanding, knowledge, skills, attitudes or behaviour. It can be an outcome of training but also education and everyday experience.[95]

Figure 1 shows the methodology used to gather and appraise the evidence used within this report and the original literature review. This includes academic evidence, grey literature, lived experience insights and the expert roundtable event.

Figure 1 Enablers and barriers of dementia training and education



[1] Identified through citation review, recommended articles, discussions with Alzheimer's Society internal colleagues.
[2] Records excluded following abstract screen, ineligible following full reading, removing duplicates.

Appendix 2
Costing methodology

iWHELD: Costs

WHELD and iWHELD have currently been delivered to circa 500 care homes. On this basis, the iWHELD programme costs approximately £2000 per year, which covers 24/7 access to the digital platform and ongoing input from coaches and senior managers to sustain benefit and quality assure the training.

The cost of delivering iWHELD to all 14,705 care homes in England would therefore be around: £29.4 million. This would include senior clinical supervision and management infrastructure.

Furthermore, a 2018 PLOS Medicine paper[97] tells us that over the nine months of the study, running the WHELD programme led to an average cost saving of £4,740 per care home, compared with usual care. After accounting for the cost of the WHELD programme, health and social care cost savings were evident, equating to approximately £2,000 per care home, per year or approximately £29.4 million for all CQC registered care homes per annum. Health and social care costs refer to accommodation costs, primary care, hospital, community health and emergency. This was calculated at a nine-month follow-up from initial intervention.

NIDUS-Professional: Costs

Considering the costs of delivering dementia training in home care settings, it cost £1,915 to deliver NIDUS-professional to four agencies in the recent feasibility trial (considering training and facilitator costs alone), or £478 per agency. Including costs for the time workers and managers spent engaging with the intervention at usual rates of pay, the average cost per agency of training provided was £1,606.

There are around 15,000[98] home care agencies in England registered with the CQC, so the estimated cost of roll out would be approximately £24 million including staff reimbursement costs. This is a relatively small cost, especially when set against the costs associated with inadequate home support. Put another way, training staff in one agency (£1,606) costs less than two weeks of full-time care in a care home.[99] So good quality home care from trained and supervised home care workers is not only what people with dementia and family carers prefer, but also far more cost effective.

While NIDUS-professional has only been tested in a feasibility trial, a recent evidence synthesis indicated that it is of a similar level of intensity (six hours of training) to other successful interventions, for example the PITCH trial in Australia.[99] NIDUS-professional is the only intervention package that has been tested in the UK in an RCT to date. It is based on the PITCH trial materials. PITCH was an intervention that increased care worker sense of competence in dementia care in a full trial. A full trial of NIDUS-professional is planned, with the intention of exploring how co-facilitation of the intervention by trained and supervised agency staff might increase buy-in and enable the content to be tailored to agency needs, while ensuring training is rigorous and evidence-based.

Appendix 3

List of professionals consulted and lived experience insights

Professor Claire Surr
Leeds Beckett University

Professor Clive Ballard
University of Exeter

Professor Karen Spilsbury
University of Leeds

Dr Kritika Samsi
Kings College London

Dr Monica Leverton
Kings College London

Dr Mark Wilberforce
University of York

Professor Christine Wilson
Queen's University Belfast

Professor Claudia Cooper
Queen Mary University of London

Professor Linda Clare
University of Exeter

Dr Deirdre Harkin
Ulster University

Nicola Jacobson-Wright
University of Worcester

Dr Isabelle Latham
Hallmark Care homes

Suzanne Mumford
Care UK

Dr Catherine Charlwood, NIHR Policy Research Unit in Dementia and Neurodegeneration University of Exeter (DeNPRU Exeter)

Nick Andrews
DEEP Cymru

Lived experience insights:

With thanks to Alzheimer's Society Health and Social Care Steering Group members who shared their lived experience insights as people living with dementia and current and former carers.

Martina Davis

Peter Riley

Bill Cavender

Katie Griffin

Ruth Chauhan

References

1. Carnall Farrar (2024), **The economic burden of dementia**.

2. UKHCA/Homecare Association (2015), **Dementia and Homecare: Driving Quality and Innovation**.

3. Wittenberg, R (2018). **The Costs of Dementia in England, Int Jr Geriatric Psychiatry**, Vol 34, Iss. 7, pp.1095-1103.

4. Skills for Care (2024). **The state of the adult social care sector and workforce in England 2024**.

5. All-Party Parliamentary Group on Dementia (2022), Workforce Matters: Putting People Affected by Dementia at the Heart of Care, p.19. 2 in 5 people surveyed reported that their care was not personalised.

6. All-Party Parliamentary Group on Dementia (2022), Workforce matters.

7. UK Public General Acts (2022), **Health and Care Act (2022)**.

8. Carnall Farrar (2024), **The economic burden of dementia**.

9. Skills for Care (2024). **The state of the adult social care sector and workforce in England 2024**.

10. See: Jane Fossey et al (2014), **The disconnect between evidence and practice: a systematic review of person-centred interventions and training manuals for care home staff working with people with dementia**. This study found widespread use of training manuals that were not evidenced based.

11. See also: SJ Smith et al (2019), **An audit of dementia education and training in UK health and social care: a comparison with national benchmark**. This study found that in 386 dementia training packages analysed in England, only 40% of the Dementia training Standards Framework learning outcomes were covered.

12. Skills for Care (2024). **The state of the adult social care sector and workforce in England 2024**, 38.

13. CQC in England, Social Care Inspectorate in Wales and Regulation and Quality Improvement Body in Northern Ireland.

14. The **Dementia Training Standards Framework** in England, the **Good Work Framework** in Wales and the **Dementia Learning and Development** Framework in Northern Ireland.

15. UK Public General Acts (2022), **Health and Care Act (2022)**.

16. UKHCA/Homecare Association (2015), **Dementia and Homecare: Driving Quality and Innovation**.

17. Wittenberg, R (2018). **The Costs of Dementia in England**, Int Jr Geriatric Psychiatry, Vol 34, Iss. 7, pp.1095-1103.

18. All-Party Parliamentary Group on Dementia (2022), **Workforce Matters: Putting People Affected by Dementia at the Heart of Care**. The survey that underpins the APPG report was undertaken in England. However, we consider the specialist needs identified applicable across nations.

19. All-Party Parliamentary Group on Dementia (2022), **Workforce Matters: Putting People Affected by Dementia at the Heart of Care**, p.19. See also: Schulz et al (2015), **Participation in cognitively-stimulating activities is associated with brain structure and cognitive function in preclinical Alzheimer's disease**.

20. Woods B, Rai HK, Elliott E, Aguirre E, Orrell M, Spector A (2023). **Cognitive stimulation to improve cognitive functioning in people with dementia**. Cochrane Database of Systematic Reviews 2023, Issue 1. Pub3

21. All-Party Parliamentary Group on Dementia (2022), **Workforce Matters: Putting People Affected by Dementia at the Heart of Care**. The survey that underpins the APPG report was undertaken in England. However, we consider the specialist needs identified applicable across nations.

22. Ibid

23. Ibid

24. Skills for Care (2024). **The state of the adult social care sector and workforce in England 2024**.

25. Walnut (2024), Personal Experiences of the Dementia Journey: The True Picture (no link available at present).

26. Skills for Care (updated 2024), **Statutory and mandatory training guide for adult social care employers**.

27. Ibid

28. Nice Guideline (2018), **Dementia: assessment, management and support for people living with dementia and their carers**.

29. Care Quality Commission (2024), **Regulation 18: staffing**.

30. Social Care Wales (2023), **Social care workforce survey 2023**.

31. Social Care Wales (2023) **Registration changes for social care workers and managers**.

32. Social Care Wales (2023), **All Wales Induction Framework Section 3 'Health and Wellbeing**.

33. Guidance to Regulation 36 of The Regulation and Inspection of Social Care (Wales) Act 2016 contains reference to social workers completing the relevant induction programme required by Social Care Wales, although, as set out above, it is unclear whether and how this is monitored.

34. Skills for Care (2024). **A Workforce Strategy for Adult Social Care in England**.

35. Labour Party (2024). **Manifesto**.

36. HM Government (2024), **Employment Rights Bill**.

37. Welsh Government (2023), **Proposals for a pay and progression framework for the social care workforce in Wales**.

38. Northern Ireland Social Care Council (2024). **What does the Care in Practice Framework mean for you and your staff?**

39. Care Quality Commission (last updated 2024), **Regulation 18: staffing**.

40. National Institute for Health and Care Excellence (last updated 2023). **Dementia: assessment, management and support for people living with dementia and their carers**.

41. Skills for Care (2023), **The state of the adult social care sector and workforce in England**.

42. In England, in 2023 the turnover rate for care workers was 13.3%, with a vacancy rate of 7.2% as of September 2023 (**The workforce employed by adult social services departments England 2023**, skillsforcare.org.uk). while 390,000 people left their job in 2022/23 - one third of whom left social care altogether (Skills for Care, 2023, **The state of the adult social care sector and workforce in England**, p.19). In Wales, the social care workforce has approximately 5,323 vacancies recorded, equivalent to a vacancy rate of 9% in total, from a total number of 84,134 people estimated to work in the social care sector (Social Care Wales, **Social Care Workforce Report 2022**, p. 10). In Northern Ireland, on 31 March 2024, the leaving rate of Health and Social Care staff was 7.7% during the prior year. This is a decrease from the rate of 8.4% reported in 2023. The joining rate of Health and Social Care staff on 31 March 2024 was 9.3%. At 31 March 2024, the Social Services staff group made up the highest proportion of all vacancies actively being recruited, at 25.7%, equating to 1,381 vacancies (Department of Health, 2024, **Northern Ireland Health and Social Care Active Recruitment Statistics & Northern Ireland Health and Social Care Workforce Statistics March 2024**).

43. Skills for Care (2024). **A Workforce Strategy for Adult Social Care in England**, 39.

44. Steinberg, M. et al (2008). **Point and 5-year period prevalence of neuropsychiatric symptoms in dementia: the Cache County Study**. Int Jr Geriatric Psychiatry, Vol. 23, Iss. 2, 170–177

45. Wittenberg R, Knapp M, Hu B, et al. **The costs of dementia in England**. Int J Geriatr Psychiatry. 2019; 34: 1095–1103.

46. Kim, D. et al (2024). '**How Do Nursing Home Nurses Conceptualize the Management of Behavioral and Psychological Symptoms of Dementia? A Phenomenographic Study**'. Nurs Health Sci Vol. 26, Iss. 1.

47. Spector, A. et al (2013). '**A Systematic Review of Staff Training Interventions to Reduce the Behavioural and Psychological Symptoms of Dementia**'. Ageing Res Rev Vol. 12, Iss. 1, pp. 354–64.

48. This statement can be justified from WHELD study findings. NIHR (2023) **Digital training programme improves quality of life for care residents with dementia | NIHR**

49. Ballard C, Corbett A. **Agitation and aggression in people with Alzheimer's disease**. Curr Opin Psychiatry. 2013; 26(3): 252-259.

50. Martyr, A et al (2019). '**Living Well with Dementia: A Systematic Review and Correlational Meta-Analysis of Factors Associated with Quality of Life, Well-Being and Life Satisfaction in People with Dementia**'. Psychol Med Vol. 48, Iss. 13, pp. 2130–39.

51. Costello, H. et al (2019). '**International Psychogeriatrics 31, no. 8 (August 2019): 1203–16.A Systematic Review and Meta-Analysis of the Prevalence and Associations of Stress and Burnout among Staff in Long-Term Care Facilities for People with Dementia**'. Int Psychogeriatr Vol. 31, Iss. 8, pp. 1203–16.

52. Möhler R, Richter T, Köpke S, Meyer G. **Interventions for preventing and reducing the use of physical restraints for older people in all long-term care settings**. Cochrane Database Syst Rev. 2023 Jul 28;7(7):CD007546. doi: 10.1002/14651858.CD007546.pub3. PMID: 37500094; PMCID: PMC10374410.

53. Ballard, C., et al. "**Improving Mental Health and Reducing Antipsychotic Use in People with Dementia in Care Homes: The Wheld Research Programme Including Two RCTs**." Programme Grants for Applied Research 8, no. 6 (2020).

54. 53. Rozing, M et al (2023), **Use of hypnotic-sedative medication and risk of falls and fractures in adults: A self-controlled case series study**. Wiley Online Library. Volume 148, Iss 5, pp: 394-404.

55. Muhlbauer, V et al (2017), **Antipsychotics for agitation and psychosis in people with Alzheimer's disease and vascular dementia**. Cochrane Library.

56. Polascek, M. et al (2020) "**'I Know They Are Not Trained in Dementia': Addressing the Needs for Specialist Dementia Training for Home Care Workers**." Health Soc Care Community Vol. 28, Iss. 2, pp.: 475-84.

57. Parveen, S. et al (2013). **Ethnicity, familism and willingness to care: important influences on caregiver mood?** Aging Ment Health, Vol. 17, 115-124.

58. Leverton M, et al (2021). **Supporting independence at home for people living with dementia: a qualitative ethnographic study of homecare - PubMed** (nih.gov). Soc Psychiatry Psychiatr Epidemiol. Vol. 56, Iss. 12, pp. 2323-2336.

59. Care Quality Commision (2023). **Rapid literature review: Inequalities in dementia**.

60. Skills for Care (2023), **The State of the Adult Social Care Sector and Workforce in England**.

61. National Institute for Clinical Excellence (2018). **Dementia: assessment, management and support for people living with dementia and their carers**.

62. Rasmussen, B. M. et al (2023) "**Effectiveness of Dementia Education for Professional Care Staff and Factors Influencing Staff-Related Outcomes: An Overview of Systematic Reviews**." International Journal of Nursing Studies Vol. 142.

63. Dow, Briony, Steven Savvas, Christa Dang, Frances Batchelor, Colleen Doyle, Claudia Cooper, Gill Livingston, et al. '**Promoting Independence Through Quality Dementia Care at Home (PITCH): An Australian Stepped-Wedge Cluster Randomised Controlled Trial Evaluating a Dementia Training Program for Home Care Workers**'. International Journal of Geriatric Psychiatry 39, no. 9 (2024): e6140. **https://doi.org/10.1002/gps.6140**

64. 63. Newbould, L. et al "**Developing Effective Workforce Training to Support the Long-Term Care of Older Adults: A Review of Reviews**." Health Soc Care Community Vol. 30 pp. 2202-17.

65. Education and training in dementia care: A person-centred approach by Claire Surr, Sarah Jane Smith and Isabelle Latham. Publisher: Open International Publishing. Published 2023.

66. Islam, M. et al (2017). "**The Nature, Characteristics and Associations of Care Home Staff Stress and Wellbeing: A National Survey**." BMC Nursing Vol. 16 Art. 22.

67. Rasmussen, B. M. et al (2023). "**Effectiveness of Dementia Education for Professional Care Staff and Factors Influencing Staff-Related Outcomes: An Overview of Systematic Reviews**." International Journal of Nursing Studies Vol. 142.

68. Newbould, L. et al (2022). "**Developing Effective Workforce Training to Support the Long-Term Care of Older Adults: A Review of Reviews**." Health Soc Care Community Vol. 30, pp. 2202-17.

69. Parveen S, Smith SJ, Sass C, Oyebode JR, Capstick A, Dennison A, Surr CA. **Impact of dementia education and training on health and social care staff knowledge, attitudes and confidence: a cross-sectional study**. BMJ Open. 2021 Jan 19;11(1):e039939. PMCID: PMC7817792.

70. Rasmussen, B. M. et al (2023). "**Effectiveness of Dementia Education for Professional Care Staff and Factors Influencing Staff-Related Outcomes: An Overview of Systematic Reviews**." International Journal of Nursing Studies Vol. 142.

71. Brooker DJ, Latham I, Evans SC, Jacobson N, Perry W, Bray J, Ballard C, Fossey J, Pickett J. **FITS into practice: translating research into practice in reducing the use of anti-psychotic medication for people with dementia living in care homes**. Aging Ment Health. 2016 Jul;20(7):709-18.Epub 2015 Jul 13. PMID: 26167720; PMCID: PMC4898161.

72. NIHR (accessed September 2024), **WHELD into Practice: improving Wellbeing and mental HEaLth for care home residents with Dementia and reducing unnecessary sedative medications**.

73. University of Worcester, Association of Dementia Studies (2014), "**FITS into Practice" Developing Dementia Specialist Care Homes Summary Report**.

74. Alzheimer's Society and Carnall Farrar (2024). **The economic impact of dementia – Module 2: Dementia's contribution to health metrics**.

75. Ibid.

76. Delray, S et al (2024). **Systematic policy and evidence review to consider how dementia education and training is best delivered in the social care workforce, and how policy does or can enable its implementation in England**. NB: This article is a preprint and has not been peer-reviewed. It reports new medical research that has yet to be evaluated and so should not be used to guide clinical practice.

77. Brooker DJ, Latham I, Evans SC, Jacobson N, Perry W, Bray J, Ballard C, Fossey J, Pickett J. **FITS into practice: translating research into practice in reducing the use of anti-psychotic medication for people with dementia living in care homes**. Aging Ment Health. 2016 Jul;20(7):709-18. Epub 2015 Jul 13. PMID: 26167720; PMCID: PMC4898161.

78. McDermid, J. et al (2024). '**Impact of the iWHELD Digital Person-Centered Care Program on Quality of Life, Agitation and Psychotropic Medications in People with Dementia Living in Nursing Homes during the COVID-19 Pandemic: A Randomized Controlled Trial**'. Alzheimers Dementia Vol. 20, Iss. 3, pp. 1797–1806.

79. Ballard C, M. et al (2020). **Improving mental health and reducing antipsychotic use in people with dementia in care homes: the WHELD research programme including two RCTs**. Programme Grants Appl Vol. 8, Iss. 6.

80. Fossey J, Garrod L, Guzman A, Testad I. **A qualitative analysis of trainer/coach experiences of changing care home practice in the Well-being and Health in Dementia randomised control trial**. Dementia. 2020;19(2):237-252.

81. Modelled on PITCH, the Australian evidence-based education program for HCWs supporting people living with dementia and their families at home.

82. Cooper, C., et al (2024). "**Feasibility and Acceptability of Nidus-Professional, a Training and Support Intervention for Homecare Workers Caring for Clients Living with Dementia: A Cluster-Randomised Feasibility Trial**." Age Ageing Vol. 53, Iss. 4.

83. Kelleher, D. et al (2024). '**A Process Evaluation of the NIDUS-Professional Dementia Training Intervention for UK Homecare Workers**'. Age Ageing Vol. 53, Iss. 5.

84. Cooper, C. et al (2024). "**A Psychosocial Goal-Setting and Manualised Support Intervention for Independence in Dementia (NIDUS-Family) versus Goal Setting and Routine Care: A Single-Masked, Phase 3, Superiority, Randomised Controlled Trial**." Lancet Healthy Longevity Vol. 5, pp. e141–51.

85. Care Quality Commission (accessed 19 September 2024), CQC registered **home care agencies**. NB: this is a 'live' number that is updated regularly.

86. Ballard, C et al (2018). **Impact of person-centred care training and person-centred activities on quality of life, agitation, and antipsychotic use in people with dementia living in nursing homes: A cluster-randomised controlled trial**. PLOS Medicine. Table 5.

87. Age UK estimates that residential care costs around £800 per week in a care home, and £1708 per week in a nursing home. See: Age UK (2024), **How much does care cost?**

88. Education and training in dementia care: **A Person-centred Approach. Education and Training in Dementia Care: A Person-Centred Approach** (Paperback). Surr, C; Latham, I; Smith, SJ. 2023. Chapt 9.

89. **leedsbeckett.ac.uk/research/centre-for-dementia-research/what-works/**

90. Michie, S., van Stralen, M.M. & West, R. **The behaviour change wheel: A new method for characterising and designing behaviour change interventions**. Implementation Sci 6, 42 (2011). **https://doi.org/10.1186/1748-5908-6-42**

91. Harvey, G., Kitson, A. **PARIHS revisited: from heuristic to integrated framework for the successful implementation of knowledge into practice**. Implementation Sci 11, 33 (2015). **https://doi.org/10.1186/s13012-016-0398-2**

92. Atkins, L., Francis, J., Islam, R. et al. **A guide to using the Theoretical Domains Framework of behaviour change to investigate implementation problems**. Implementation Sci 12, 77 (2017). **https://doi.org/10.1186/s13012-017-0605-9**

93. Surr, Claire, Sarah Jane Smith, and Isabelle Latham. **Education and Training in Dementia Care: A Person-Centred Approach**. Open International Publishing, 2023.

94. Footnote: Experts acknowledge that in relation to dementia care, leaders within organisations can come from a diverse range of roles and may not be the most obvious person, such as those in housekeeping.

95. The King's Fund (2024), **The adult social care workforce in a nutshell**.

96. Based on definition from Surr. C; Smith, S.J Latham I. **Education and Training in Dementia Care: A Person-Centred Approach**. Open University Press (6 Mar. 2023)

97. Ballard, C et al (2018). **Impact of person-centred care training and person-centred activities on quality of life, agitation, and antipsychotic use in people with dementia living in nursing homes: A cluster-randomised controlled trial**. PLOS Medicine. Table 5.

98. Care Quality Commission (accessed 19 September 2024), CQC registered **home care agencies**.

99. Age UK estimates that residential care costs around £800 per week for a care home and £1078 per week for a nursing home. See Age UK, **How much does care cost?**

100. Dow B, Savvas S, Dang C, Batchelor F, Doyle C, Cooper C, Livingston G, Wise E, Tan E, Panayiotou A, Malta S, Clarke P, Burton J, Low LF, Loi SM, Fairhall A, Polacsek M, Lyketsos C, Scherer S, Ames D, Engel L, Goh AMY. **Promoting Independence Through Quality Dementia Care at Home (PITCH): An Australian Stepped-Wedge Cluster Randomised Controlled Trial Evaluating a Dementia Training Program for Home Care Workers**. Int J Geriatr Psychiatry. 2024 Sep;39(9):e6140.

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