Good Practice in Care for Those Living with a Dementia: Literature Review

IFF Research, in partnership with Leeds Beckett University,
on behalf of the Care Quality Commission

March 2026

Contents

Glossary of key terms

Key term	Definition
Advance Care Planning (ACP)	A voluntary, person-led process in which an individual discusses their preferences and priorities for future care with their care providers while they have the mental capacity to do so. It usually involves several conversations over time and ensures that the person’s wishes and emotions are respected. The aim is to give the individual a stronger sense of involvement and the opportunity to reflect on and share what matters most to them.
Care Quality Commission (CQC)	The Care Quality Commission (CQC) is the independent regulator of health and adult social care in England. CQC registers, inspects and monitors health and adult social care providers. It was established in 2009 under the Health and Social Care Act 2008.
Case conference	A structured team meeting where caregivers and health professionals discuss a person's complex care needs, identify the root causes of expressions of distress, emotions or unmet needs, and develop individualised strategies to improve their quality of life.
Dementia	Dementia is an umbrella term for a group of progressive, irreversible symptoms of cognitive impairment, including changes in memory, thinking, and reasoning. Dementia interferes with a person’s daily activities and social functioning. Different diseases can cause dementia, with the most common being Alzheimer’s disease.
Dementia-friendly environment	An environment designed to be accessible and supportive for people living with a dementia, reducing stigma and promoting inclusion. This can involve adaptations in public spaces, businesses, and community services to make them more accommodating for individuals with a dementia.
Equalities and human rights	Ensures that care for those living with a dementia and their family/carers respects diverse backgrounds, identities, and rights. In the UK, it is illegal to discriminate against anyone because of their protected characteristics (see below).
Person-centred care	An approach to care that ensures individuals’ preferences, needs, and values guide clinical decisions, ensuring they are at the centre of their care and involved in shared decision-making.
Person-led care	A progression from person-centred care, focusing on empowering individuals with a dementia to shape and lead their own care experiences.
Positive risk taking	An approach that balances the potential hazards against the benefits of independence, dignity, and meaningful engagement for people living with a dementia. It involves accepting measured risks to enhance autonomy and quality of life.

Key term	Definition
Protected characteristics	Legal categories under the Equality Act 2010 that are illegal to discriminate on the basis of. These are: age; gender reassignment; being married or in a civil partnership; being pregnant or on maternity leave; disability; race including colour, nationality, ethnic or national origin; religion or belief; sex; sexual orientation. Discrimination is prohibited in settings of work, education, as a consumer, using public services, buying or renting a property, and as a member or guest of a private club or association.
Young-onset dementia	A diagnosis of a dementia in people under the age of 65. It is also often referred to as early-onset or working-age dementia.

1 Executive summary

Dementia is an umbrella term for a range of conditions that makes it hard for people to remember things, think clearly, and talk to others. It can make everyday activities more challenging for people and affect the quality of life for the person living with a dementia and those around them.

In the UK, about 982,000 people have a dementia, and this number is expected to grow to 1.4 million by 2040 (Alzheimer's Society, 2024). As more people get a dementia, health and social care services (e.g. care homes, hospitals and GPs) will face more pressure. This means that providing good quality care for those living with a dementia is very important (Alzheimer's Society, 2025).

To help improve care for people living with a dementia, the Care Quality Commission (CQC) asked IFF Research and Professor Sarah Smith at the Centre for Dementia Research (Leeds Beckett University) to do a review of good practice in supporting those living with a dementia in the UK and around the world. CQC is an organisation that monitors, inspects and registers health and care providers, and they publish what they find. Where they find poor care, they use their powers to take action. This is known as a regulator, and CQC is the independent regulator of health and adult social care in England.

The review aimed to identify the things that make care good quality and ensure people have a good experience of the care they receive, including the conditions that help them succeed. The results will help CQC create clear guidance for care services and set a consistent definition of "what good looks like" across care for those living with a dementia and their family/carers.

IFF reviewed documents published by universities, and organisations in health and social care. Out of 2,704 documents, 61 were chosen for detailed analysis. The review also included three discussion groups with experts, other regulators of health and social care, and people with lived experience of a dementia or caring for someone with a dementia.

The key findings from the review are shown below, with more detail in the main report.

Person-led care

Most of the literature reviewed referred to person-centred care. Person-centred care required inclusion of people with lived experience of a dementia and their support networks in decision-making; recognition of people's life stories and preferences; and support that is adapted to individuals' needs.

Person-led care means that the person is in charge of their own care. They make choices about what happens, and staff support them to lead the way. It is about making sure care is consistent, accessible, gives them control, and helps them feel confident and safe (Dementia Services Development Centre: Person Centred vs Person Led; Care Inspectorate Scotland, 2017). This approach not only recognised people living with a dementia as individuals but also enabled them to shape and lead their own care.

What good looks like

Making care plans together with people living with a dementia and their carers/families, not for them. Care plans should be 'living documents' that change as needed. Plans should cover all parts of life, not just medical needs (e.g. social activities, hobbies, and cultural preferences) (Care Inspectorate Scotland (2017)).

Bosco et al. (2019) found that when people living with a dementia were actively involved in planning their care, it improved the overall quality of care they received. Moenke et al. (2023) showed that including information about them, such as a person's life history, interests, and values, helped shape care plans that were more individualised and meaningful.

Social interaction was a key element of good dementia care. Evidence showed that structured, meaningful, and inclusive activities not only supported wellbeing but also reduced symptoms of dementia, such as agitation (Ballard et al., 2018).

Evidence suggested that training care staff, e.g. via the Well-being and Health for People Living with Dementia (WHELD) intervention[1], to tailor social activities to people's interests and abilities, improved quality of life (Ballard, C. et al. (2018).

Activities were often framed around daily life tasks, such as table setting, ironing, or hand-eye coordination exercised like squeezing or pouring (Yan et al., 2022). Treadaway et al. (2018) also talked about the positive role of creative and playful activities in enhancing social engagement. For example, a simulated "road trip" to get ice cream produced more engagement than conventional conversation.

Opportunities to feel part of a community allowed people to continue exercising choice and control in their lives. Family and carers also played a central role in enabling social connection. Bosco et al. (2019) highlighted the importance of including carers within care planning to preserve dignity, noting that family members wanted their loved ones to be remembered as the person they were, while being treated with respect as individuals in the present.

Peer support approaches[2] also demonstrated how strong relationships reduced isolation, challenged stigma, and promoted wellbeing (Stott et al., 2017). Stott et al. (2017) found that people living with a dementia employed as peer support workers experienced a higher quality of life through developing new skills, making social connections, and feeling less isolated.

---

[1] Ballard et al. (2018) ran a RCT in 69 UK care homes to test the WHELD programme. Staff were trained in person-centred care, meaningful social interaction, and antipsychotic use review. A "care staff champion" model supported ongoing delivery.

[2] This happens when people with similar long-term conditions, or health experiences, come together to support each other – either on a one-to-one or group basis. It is enabled through relationships that build mutual acceptance and understanding.

A strong sense of home was associated with helping people to keep doing things that were important to them (Halton, Liverpool and Wirral Borough Councils, 2018). Post-diagnostic support programmes like Beyond the Front Door, developed by Halton, Liverpool and Wirral Borough Councils, highlighted that people living with a dementia and their family/carers valued opportunities to reflect on what 'home' meant and how this could be maintained as care needs changed (e.g. going into a care home).

Cultural similarities were equally important across all care settings. Respecting (where possible) people's preferences to be supported by someone from their own community, who could speak their language and relate culturally, helped maintain trust, identity, and a sense of belonging.

Physical environments also shaped how inclusive care settings could be. Research showed that smaller-scale, homelike settings encouraged comfort, participation, and engagement in daily life (Woodbridge et al., 2018; D'Cunha et al., 2023). Spaces designed around familiarity and accessibility, such as safe outdoor areas, quiet rooms, and flexible communal spaces, helped reduce disorientation and supported autonomy. By contrast, institutional or task-oriented environments risked undermining person-led care.

Assessments of dementia diagnostic centres in England found several features that made environments difficult for people living with a dementia to navigate, including a lack of dementia-friendly signage, limited use of contrasting colours in corridors and toilets, and disruptive noise from building works (Healthwatch England, 2024).

Things to help achieve this

Training staff to communicate well, even without using words (e.g. body language and non-verbal cues) was important. Without training, staff could unintentionally undermine someone living with a dementia (e.g., ignoring them or treating them like children).

Roundtable discussions also pointed to wider factors that helped achieve good quality care: having enough staff, and giving staff the time to build relationships were important. Effective leadership was also identified as key to creating cultures where staff felt permitted to prioritise relationships and small, everyday acts of care.

A number of tools for evaluating good practice were mentioned in the roundtables and could be valuable for CQC to encourage the use of. These included Dementia 100 Pathway Assessment Tool[3] and University of Stirling developed the Environments for Ageing and Dementia Design Assessment Tool (EADDAT)[4].

Equalities and human rights

This means making sure that care for those living with a dementia and their family/carers respects different backgrounds, identities, and rights. This is regardless of someone’s age, gender reassignment, marriage or civil partnership, pregnancy or maternity leave, disability, race including colour, nationality, ethnic or national origin, religion or belief, sex, or sexual orientation (together, these are known as protected characteristics).

What good looks like

Access to care for those living with a dementia was improved by using online tools. This included using video calls to help people living with a dementia to get good quality care, especially when living in rural areas.

Cultural understanding helped build a trusting care experience. The quality of care for those living with a dementia improved when care providers understood the cultural backgrounds of those living with a dementia and their carers (Seetharaman *et al.*, 2022; The King’s Fund, 2024). Participants in the roundtable discussions highlighted food as a key factor that affects people’s experience with dementia support, particularly for racially minoritised communities. Informal dementia support groups enticed people to participate by providing culturally relevant foods (mentioned with reference to South Asian communities), while another group cooked hot meals for people from Caribbean backgrounds.

Local community support groups promoted access to dementia services by providing an accepting space for people to talk about dementia or just to be around other people. This was particularly true for those with protected characteristics, such as sexual orientation and religion, who may feel more comfortable around people living with a dementia who are similar to them.

---

[3] Developed by NHS England, the Department for Health and Social Care (DHSC), and other partners, the Dementia 100 Pathway Assessment Tool brought together best practice standards for dementia care into one self-assessment framework. The relatively new tool was designed for systems to conduct self-assessments at a place-based level, rather than for use by individual providers.

[4] This combined a set of design principles covering layout, lighting, signage, acoustics, and outdoor spaces, with a digital assessment tool to score environments and provide recommendations for improvement (Aikman, 2023). This helped families, professionals, and organisations identify practical adaptations that could make settings more accessible and inclusive.

A final consideration with human rights was the tension between safety and privacy. As identified in the roundtables, care providers had a responsibility to keep those supported safe and free from harm. On the other hand, those who participated in the lived experience roundtable placed a high value on their privacy and freedom to move around as they wish. Good practice involves a careful and explicit consideration of this balance.

Things to help achieve this

Building staff confidence and skills was essential for delivering good quality care for everyone living with a dementia. This was particularly the case using digital or online tools, such as videoconferencing. The consideration of digital skills also extended to those living with a dementia and their carers.

Beyond training, support for those living with a dementia and their carers benefitted from a workforce that reflected the demographics (e.g. ethnicity) of local communities (Weiss *et al.*, 2020). This was a key enabler for culturally sensitive and inclusive care.

Roundtable participants pointed to several conditions that allowed for strong community connections to flourish. These included collaboration across local partners (e.g. councils, voluntary organisations, and statutory services), co-design with those living with a dementia and their families, and the involvement of diverse volunteers to build trust and inclusivity. Ensuring that dementia was understood as “everybody’s business” was also seen as essential, with shared responsibility across community stakeholders helping to reduce stigma and foster belonging.

Staffing and training

Staffing and training are important for good dementia care. By this, we mean having staff who know about dementia and how to provide proactive support. This can be achieved through staff attending training.

What good looks like

There is currently no legal requirement for all health and care staff to undertake dementia training in England. However, providers are required to ensure that staff are suitably qualified, trained and skilled to ‘meet the needs of the people using the service’ (Care Quality Commission, 2025a).

The literature recommended that all those who work with people living with a dementia and their carers have dementia-relevant skills and knowledge (van der Weide *et al.*, 2023). As a starting point, staff needed to understand the typical symptoms and needs of people living with a dementia (Jones *et al.*, 2022). This was of equal importance for those who did not work regularly or predominantly with people living with a dementia, such as hospital staff, as for those working frequently with those with a dementia (Jones *et al.*, 2022; Moody *et al.*, 2024; Goh *et al.*, 2022).

Staff desired practical and applied guidance and training, particularly around communication skills and ways of meeting needs around distress and emotions (Alzheimer's Society, 2024). Training was particularly requested in relation to communicating with people living with a dementia, as well as in recognising and interpreting body language that could signal unmet needs (Handley, Bunn and Goodman, 2017).

Things to help achieve this

Sufficient staff capacity is necessary for dementia-related training to be useful (Backhouse *et al.*, 2017; Brazil *et al.*, 2018). Staff capacity includes having sufficient numbers of staff on shift, as well as staff having manageable workloads (Handley, Bunn and Goodman, 2017; Seetharaman *et al.*, 2022). Challenges in achieving this are reflective of broader concerns in the adult social care sector, including high turnover, workforce shortages and difficulties with recruitment (Smith *et al.*, 2023).

Another enabler of effective training was the train-the-trainer model, where some staff received more in-depth training and trained other staff (Sampson *et al.*, 2017). In one example, this approach allowed for all staff across an entire hospital to be trained (Sampson *et al.*, 2017).

Leadership and culture

Leadership is when someone guides and helps others. A good leader sets a good example, listens to others, and helps everyone work together. Culture is the way people in a group or organisation do things. It includes their values, beliefs, and behaviours. A positive culture makes everyone feel included and respected.

What good looks like

Quality assurance was widely regarded as important in dementia care, with structured frameworks and audit tools being used to standardise care and demonstrate effectiveness. These approaches provided consistent assessment across health and social care, ensuring needs were met (Brazil *et al.*, 2018; Royston *et al.*, 2020). Quality assurance tools, such as audits, performance reviews, and feedback tools, created benchmarks for good practice, helped monitor care delivery, highlighted areas for improvement, and ensured accountability to people living with a dementia and their families.

Feedback and accountability mechanisms were also considered best practice as they enhanced transparency and drove continuous improvement. A good practice example was provided by Royston *et al.* (2022), who found effective use of anonymous, real-time digital platforms for those living with a dementia, families, and staff to provide live feedback.

The literature consistently emphasised the need for dementia care to move from risk-averse approaches towards balanced, positive risk-taking. This approach required weighing potential hazards against benefits such as independence, dignity, and meaningful engagement. The idea was that this supported services to replace restrictive practices with strategies that empowered those supported, while maintaining appropriate safeguards to protect safety and wellbeing (Seetharam *et al.*, 2022; Behram *et al.*, 2017; Handley *et al.*, 2017).

Effective leaders were those who promoted flexibility in workplace practices to enhance person-led care. They empowered staff to take initiative and find solutions that met the personal needs of people living with a dementia (Moenke *et al.*, 2023). Crucially, this required moving away from a task-based culture, where staff followed routines rigidly without the resources to implement person-led care principles (Care Inspectorate Scotland, 2017).

As the needs of people living with a dementia are complex, no single service could provide all of the support needed. Different support services working together helped to improve coordination, and deliver more tailored, person-led approaches. Importantly, effective partnership working not only required organisational collaboration but also the meaningful inclusion of people living with a dementia and their carers in the design and delivery of services (Aworinde *et al.*, 2024).

Things to help achieve this

Key enablers of good quality leadership and culture in dementia care included leaders acting as supportive role models, promoting diversity, and being well trained for their roles. As discussed at the roundtables, leadership development was important, ensuring individuals were upskilled before assuming managerial responsibilities.

Different support services working together was also felt to be best practice in dementia care. Effective support relied on coordination across health, social care, housing, community, and voluntary sectors, with regular meetings (and other ways) to make decisions together (Goeman *et al.*, 2016; Care Inspectorate Scotland, 2017; Gräske *et al.*, 2018; Brazil *et al.*, 2018; Local Government Association, 2018; Bosco *et al.*, 2019; Jones *et al.*, 2022; Seetharaman *et al.*, 2022).

Organisational investment (e.g. in staff development) emerged strongly from the roundtables as a critical enabler of effective leadership and a positive culture in dementia care. Though it was less frequently highlighted in the formal literature. Investing in workforce development strategies ensured that staff were equipped with the skills, knowledge, and confidence to provide person-led care, while also maintaining leadership and cultural priorities at the organisational level.

What does this mean for CQC?

CQC has an important role in making dementia care better. Through its dementia strategy, CQC can show leadership and set out a clear vision of what good care should look like. This will be an important opportunity for CQC to use their voice in the sector to support and encourage improvements in the care delivered to those living with a dementia and their carers.

CQC should also continue their active collaboration with other external dementia work, for example that led by the Department for Health and Social Care and NHS England. This will ensure learning is shared and there is a collective responsibility, no duplication of efforts, and a clarity of message for providers about ongoing work to support improvements.

A common theme across the roundtables was the desire for CQC to share good practice with care services and the public. This means showing clear, real examples of what good quality dementia care looks like, so that providers know what to aim for and people living with a dementia know what they should expect. These examples could be shared in blogs, news articles, or reports, and should be easy to read and visually engaging, so that people under time pressure can still learn from them.

Once there is a clearer view on CQC’s future assessment approach (internal work is ongoing following an external review in 2024), it will be important for good practice guidance on dementia to be mapped to the registration and inspection framework and kept updated as new good practice emerges. Linking this guidance directly to the registration and inspection framework will help inspectors make fair and consistent judgements, and give providers a clear understanding of the standards they must meet. It will also help families and carers know whether the care being given is accessible, supportive, and high-quality.

CQC should also focus on the needs of different groups, like those from racially minoritised communities, lesbian, gay, bisexual, queer or other sexual and/or gender minority (LGBTQ+) individuals, and people with less common types of dementia, to make sure everyone gets the best care possible. Right now, there is little evidence on good practice for these groups, as well as for people in rural areas, and those with young-onset or rare dementias. To address this gap, CQC should work with people with lived experience and community organisations, making sure their voices shape future guidance.

2 Introduction and research approach

Background

Dementia is an umbrella term for conditions that affects memory, thinking, and communication, often making everyday tasks challenging and impacting a person's quality of life. Currently, around 982,000 people in the UK are living with a dementia, and this number is expected to increase to 1.4 million by 2040 (Alzheimer's Society, 2024). As the number of people affected grows, this places greater demands on health and social care services. The NHS 10-Year Plan highlighted dementia as a national priority and committed to embedding community-based support, a dementia care framework, and integration of digital tools to improve experiences and outcomes for those living with a dementia and their family/carers (NHS England, 2025).

Within this context, there is an increasing imperative to establish robust, evidence-based approaches to care that can be delivered consistently and at scale.

Research objectives

The Care Quality Commission (CQC) commissioned IFF Research and Professor Sarah Smith at the Centre for Dementia Research (CDR at Leeds Beckett University), to undertake a rapid evidence review of good practice in dementia care. The review has examined current practice in the UK and internationally, identifying promising models and interventions shown to improve care quality, alongside the conditions that enable their success.

The review focused on the following research questions:

- What are the key characteristics of effective dementia care, including learning from approaches in other countries?
- What are the common conditions, drivers and features that support improvements in the quality of dementia care for people living with a dementia, and their carers and families?
- How have other regulators succeeded in improving the quality of dementia care within their area of regulation?

This research supports CQC's commitment to improving the experiences of people living with a dementia and their support networks through its role as the regulator of health and social care. The evidence from the review will inform the development of CQC's statutory guidance defining what good looks like for dementia care within regulated settings. Further detail is provided in Appendix 1.

Research approach

Below is a summary of the research approach. A more detailed breakdown can be found in Appendix 2.

We conducted a structured literature review of:

- Academic literature – we used academic journals and databases: Web of Science, Health Systems Evidence, Social Policy and Practice, CINAHL and Journal of Dementia Care, covering both UK and international studies.
- Grey literature – drawn from search engine searches as well as targeted website searches of key organisations such as other regulators, think tanks, voluntary organisations and Government sources.
- Unpublished literature – we used existing connections to access unpublished literature. IFF Research, CDR and CQC also used LinkedIn to do a call-out for publications.

All identified materials were then sifted through a two-stage screening process. Materials failing to meet criteria were excluded, with the remaining 61 documents forming the shortlist for a full, detailed review.

After analysis, we conducted three online roundtables – one with experts from academia and key sector organisations; one with health and care regulators and other system partners; and one with people with lived experience of living with or supporting someone with a dementia. The roundtables built on the literature review findings, and provided additional good practice examples, as well as perspectives on gaps in the evidence and their underlying causes. This insight (and additional follow up research where needed) has been included throughout, where it added to the literature review findings.

Limitations of the literature review

Scope of the review: The review was intentionally broad in scope, covering all types and stages of dementia, a person's care journey from the point of diagnosis to end of life care, and all settings regulated by CQC. As a result, initial searches returned 2,704 documents for consideration. The full inclusion and exclusion criteria can be found in Appendix 2.

As a result, it has not been possible to capture every example of good practice, and findings should not be interpreted as exhaustive or definitive. The evidence summarised represents what was identified through the agreed search strategy and inclusion / exclusion criteria, rather and a complete account of all existing good dementia care practice.

Given the broad scope of the review, it has also not been possible to cover good practice relating to every setting regulated by CQC or every stage of someone's dementia journey. Where findings relate to a specific setting or stage, this is highlighted within the report.

Unpublished literature: Much of the innovative dementia care practice is unpublished (e.g. small-scale evaluations, local pilots, or practice-based learning). Despite efforts to reach out through networks and social media, only three unpublished literature documents were included within the review. Though more examples were gathered via the roundtables.

3 Person-led care

Key findings

Person-centred care required meaningful inclusion of people with lived experience of a dementia and their support networks in decision-making; recognition of personal histories and preferences; and flexible systems and practices within health and care services that adapted to individuals. Person-led care builds on this and places greater emphasis on control, choice, consistency, and confidence.

Key features included adapting support to the person, flexible planning, and sustained support from diagnosis to end of life. Care plans were expected to be co-developed and regularly reviewed to remain fit-for-purpose.

Evidence gaps remained in relation to the measurement of the outcomes of person-led care.

Defining person-centred and person-led care

Most of the literature referred to person-centred care, rooted in Kitwood's model of dignity, respect, and recognition of personhood (Kitwood, 1997). More recently, some authors described a shift towards person-led care, which emphasised control, choice, consistency, and confidence (Dementia Services Development Centre: Person Centred vs Person Led; Care Inspectorate Scotland, 2017). This approach not only recognised people living with a dementia as individuals but also enabled them to shape and lead their own care.

Key features of person-led care included adapting support to the person rather than fitting them into rigid systems and giving staff the flexibility to tailor care to individual needs and preferences (Mitchell & Agnelli, 2015; Chenoweth et al., 2015). Roundtable discussions reinforced this, highlighting the importance of flexible planning, meaningful involvement in decisions, and sustained support from diagnosis to end of life, ideally through a single, consistent point of contact to navigate health, social care, and other services (Crowther et al., 2025). This aligned with the NHS' emphasis on shared decision-making as a core element of best practice, which set out clear hallmarks such as supporting people to understand their options, ensuring decisions reflected individual preferences, and making choices jointly between professionals and those they supported (NHS England, 2022).

Person-led care built on Kitwood's framework while extending it, retaining respect for personhood but placing greater emphasis on agency, autonomy, and influence over daily life and future care. In this report, both person-led and person-centred care are used to reflect the terminology used in the literature and roundtables[5].

---

[5] Note the vast majority of the literature used person-centred and the terms were often used interchangeably during the roundtables.

Key features of good quality care

Care plans

A core feature of person-led care was the co-development of care plans that reflected preferences, interests, and communication needs. According to Care Inspectorate Scotland (2017), these were expected to be "living documents," reviewed at least every six months, or sooner if needs changed, to remain responsive and fit-for-purpose. The Standards of Care for Dementia in Scotland required that personal plans were developed with, rather than for, people living with a dementia, in consultation with carers and families where appropriate. Plans were expected to set out how health and wellbeing needs would be met and to include wishes, choices, communication needs, equipment or adaptations, and details of who should be contacted about concerns or complaints. Independent advocacy was also expected to be available.

Inspectors in Scotland assessed whether personal plans reflected people's wishes, values, and beliefs and whether this informed daily life positively. In residential settings, they also checked whether residents had access to advocacy, whether registers of Power of Attorney and Guardianship orders were in place, and whether appropriate Section 47 consent-to-treatment certificates had been obtained (Care Inspectorate Scotland, 2017).

Roundtable discussions highlighted that other regulators, e.g., Care Inspectorate Scotland, checked whether care plans were genuinely reflected in practice. By focusing on outcomes for individuals and incorporating feedback from people living with dementia and their families. CQC could consider incorporating this as part of their assessments.

Evidence indicated mixed practice: while some residential care settings maintained detailed, person-led plans that shaped care and promoted reminiscence through life story work, others recorded changes without updating plans or failed to ensure staff consistently used personal information. Only 43% of care homes had plans that reflected the needs and aspirations of all residents, and inspectors identified gaps in detail around health, independence, and support for memory issues (Care Inspectorate Scotland, 2017).

"What you would want to be seeing is evidence that this person has objected to this part of their day three days in a row now. So actually, we've now changed what we're doing. Or we're looking at alternatives to what we're doing... You want to see that, kind of, really dynamic and flexible things going on in practise that are then reflected in processes."

Researcher, Roundtable 1

Bosco et al. (2019) found that when people living with a dementia were actively involved in planning their care, it supported their dignity, reinforced their sense of self, and improved the overall quality of care they received. Moenke et al. (2023) showed that including information, such as a person's life history, interests, and values, helped shape care plans that were more individualised and meaningful.

Backhouse et al. (2017) reported that case managers played a central role by acting as a consistent and trusted point of contact between people living with a dementia, their caregivers, and different services. In practice, families did not have to navigate complex and fragmented health and social care systems on their own. Instead, case managers coordinated communication, ensured continuity, and connected families with timely support, which reduced family/carer burden. Goeman et al. (2016), in a systematic review of 36 studies on support roles in community dementia care, similarly highlighted that effective models shared several key components: long-term engagement, face-to-face contact, individualised education and support tailored to needs, and ongoing follow-up. They found that case management was most effective when embedded within multi-disciplinary teams, where the dementia-specific expertise of case managers was complemented by the clinical and professional skills of other health and social care practitioners. This collaborative approach enabled the development of care plans that were both comprehensive and responsive to individual needs.

The Young Dementia Network (2022) also highlighted that care plans for younger people living with a dementia should include opportunities for meaningful occupation, including supported employment where possible. Supported employment examples included adapting roles to match reduced cognitive function, offering flexible part-time schedules, and providing workplace adjustments such as memory aids or restructured tasks. These activities were identified as vital for maintaining social engagement, sustaining a sense of identity and purpose, and ensuring that care remained responsive to the distinctive needs of those diagnosed at a younger age.

Dementia case conferences provided a structured approach for care planning. These team meetings brought together those living with a dementia, their family/carers, and health and care staff to discuss complex care needs, identify the root causes of expressions of distress, emotions or unmet needs, and agree individualised strategies to improve quality of life. They enabled earlier conversations, gave family/carers time to prepare, and strengthened interdisciplinary collaboration (Luckett et al., 2022).

The literature also highlighted that care planning involved Advance Care Planning (ACP). This was a voluntary, person-centred process in which individuals discussed their future care preferences with providers while they had capacity. Through a series of structured conversations, ACP clarified treatment priorities, refusals, and values, ensuring care reflected what mattered most to the person (Brazil et al., 2018). It also involved agreement on how coordination would work across relevant care services, e.g., GPs and care home staff. Best practice increasingly involved storing ACP documentation electronically, typically within an individual's electronic health record to ensure timely accessibility by all relevant care professionals. Some systems offered limited patient access, fostering transparency and engagement in care decisions.

An effective way to conceptualise how ACP fit within broader dementia care was via an illustrative pathway, such as that provided by the National Collaborating Centre for Mental Health (NCCMH). Their implementation guide outlined dementia care pathways that included co-developed, reviewed care plans, coordinated by a named care coordinator, with documentation and next steps communicated in writing.

Social activities

Social interaction was a key element of good dementia care. Evidence showed that structured, meaningful, and inclusive activities not only supported wellbeing but also reduced neuropsychiatric symptoms such as agitation (Ballard et al., 2018). The impact of activities within communities was discussed in the 'Sensitivity to Identity' section of chapter 4: Equalities and Human Rights.

Ballard et al. (2018) conducted a randomised control trial (RCT) of the Well-being and Health for People Living with Dementia (WHELD) intervention and found a statistically significant improvement in quality of life for those in the treatment group. Training staff to create 'strengths-based care plans', which laid out social and other activities tailored to people's interests and abilities, improved quality of life. Examples of activities included reminiscence, talking with residents about their interests, walking, seated exercise, and other simple 'pleasant' activities chosen to match individual preferences. All activities in the programme were delivered within care homes, supported by trained staff.

Case Study: The WHELD Programme

Ballard et al. (2018) ran a RCT in 69 UK care homes to test the WHELD programme. Staff were trained in person-centred care, meaningful social interaction, and antipsychotic use review. A "care staff champion" model supported ongoing delivery.

WHELD significantly improved quality of life, reduced agitation and neuropsychiatric symptoms, and was cost-saving compared with usual care. Benefits were greatest for people with moderately severe dementia. Training and empowering staff to embed person-centred approaches, organise person-tailored activities, and review antipsychotic use improved outcomes and reduced costs.

Source: 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 living with a dementia living in nursing homes: A cluster-randomised controlled trial', PLoS Med, 15(2), e1002500. doi: 10.1371/journal.pmed.1002500.

Yan et al. (2022), the only literature on the topic in this review[6], discussed how Montessori-based approaches were used in dementia care and highlighted several factors that supported good practice. These programmes used non-pharmacological, person-centred activities that relied on familiar materials, step-by-step tasks, and guided repetition. The aim was to support autonomy, dignity, and active engagement, while fostering meaningful social connection and a sense of achievement. Activities were tailored to the individual's cognitive abilities and were often framed around daily life tasks, such as table setting, ironing, or hand-eye coordination exercised like squeezing or pouring.

The Yan review found that shorter, individual sessions (usually under one hour), were more effective, as people with a dementia tended to tire quickly. Programmes also showed better engagement when participation lasted less than a year, suggesting that long-term repetition could reduce interest.

Montessori-based activities helped to reduce agitation and improve emotional expressions. They also supported feeding abilities by training hand-eye coordination and involving practical tasks, such as preparing table settings or household activities related to daily life. The review also highlighted that involving family carers in Montessori training was beneficial, improving the mood of people living with a dementia, although the evidence for broader effects on depression was less clear.

Yan et al. (2022) concluded that Montessori-based programmes were most effective when activities were tailored to the individual's abilities and structured to accommodate fatigue. The review highlighted the importance of person-centred, non-pharmacological interventions in promoting autonomy, engagement, and a sense of achievement, thereby improving the quality of life for people living with a dementia in residential care.

Treadaway et al. (2018) demonstrated the role of creative and playful activities in enhancing social engagement. For example, a simulated "road trip" to get ice cream produced substantially more interaction than attempts at conventional conversation. Staff involved reported that it was "absolutely the most interaction I have ever seen from him. It was absolutely amazing … it was!". Play-based activities such as this created enjoyable, shared experiences that supported greater participation.

---

[6] Note 11 documents were highlighted in the initial search, but were excluded primarily at Level 2 (see Appendix) due to limited quality of evidence.

Case Study: Creative Play to Enhance Engagement

Treadaway et al. (2018), through the LAUGH design project, explored creative, co-designed objects to stimulate engagement and wellbeing among people living with an advanced dementia. They used a Compassionate Design framework; a design approach that emphasises kindness, personalisation, and meaningful connections for people with advanced dementia.

The design process was highly participatory, involving people living with a dementia, their family/carers, and multidisciplinary designers. Playful, personalised artefacts, such as an interactive steering wheel, fidget jewellery, light-and-sound hand-held objects, and a comforting "HUG" were developed according to three core principles:

- Personalisation: Objects were tailored to reflect individual histories and preferences.
- Sensory stimulation: Items engaged touch, sight, or sound to evoke emotional responses.
- Connection: Objects encouraged connections with others, memories, or environments.

Through co-design and the Compassionate Design lens, personalised, sensory-rich objects offered moments of joy, connection, and communication - even in advanced stages of dementia. These creative interventions demonstrated how bespoke, playful artefacts can foster engagement, preserve personhood, and deliver meaningful emotional and behavioural benefits.

Source: Treadaway, C., Taylor, A. and Fennell, J. (2018) ‘Compassionate design for dementia care’, International Journal of Design Creativity and Innovation, 7(3), pp. 144–157. doi: 10.1080/21650349.2018.1501280.

Tried-and-tested everyday activities were also valued. Roundtable participants emphasised that person-led care did not necessarily require complex interventions. Many individuals valued opportunities to engage in household tasks, such as washing up or folding laundry. These tasks enabled them to contribute meaningfully and maintain continuity with roles and routines that had been central throughout their lives.

Social connection

Inclusion was one of the key psychological needs in Kitwood’s model of person-centred dementia care (Kitwood, 1997; Mitchell & Agnelli, 2015), while research on co-production highlighted the importance of sustaining belonging and social roles to promote personhood (Bosco et al., 2019). Opportunities to feel part of a community and engage in meaningful connections created conditions for people to continue exercising choice and control in their lives.

Family and carers played a central role in enabling social connection. Bosco et al. (2019) highlighted the importance of including carers within care planning to preserve dignity, noting that family members wanted their loved ones to be remembered as the person they were, while being treated with respect as individuals in the present. Carers themselves benefited from being recognised as partners in care rather than passive bystanders, as shown by Chenoweth (2016), where a structured coaching programme had built carers' confidence, supported their wellbeing, and enabled them to take a more active role in care, with opportunities for peer support further strengthening their role as partners.

The value of relational care within formal settings was also highlighted. Relational care prioritised trusting, meaningful relationships between people living with a dementia, their families, and care staff, recognising that wellbeing and autonomy were shaped through these connections. Seetharaman et al. (2022), reviewing best practice in long-term residential care, recommended care environments that accommodated family overnight stays and directly involved relatives in training and planning. These approaches supported continuity of relationships, avoided "cutting off" family connections when a person moved into a care home, and helped preserve social bonds across the care pathway.

Peer support approaches also demonstrated how strong relational ties reduced isolation, challenged stigma, and promoted wellbeing (Stott et al., 2017). Stott et al. (2017) found that people living with a dementia employed as peer support workers experienced a higher quality of life through developing new skills, making social connections, and feeling less isolated.

Case Study: Commonwealth of Peer Support, London Borough of Brent (Peer Support Programme)

As part of Brent's Dementia Strategy, Community Action Dementia (CAD) Brent launched a Peer Support Programme where people recently diagnosed with a dementia and their family/carers connected and supported each other.

Facilitated by local authority partners and the Brent Carer's Centre, the programme recruited peer supporters and began group meetings for both diagnosed individuals and family/carers.

One participant, diagnosed at 47, reported that becoming a peer supporter greatly improved their mood, self-worth, and motivation to advocate for living well with a dementia. Wider evidence suggested that this peer-led support initiative empowered participants (and particularly those with young-onset dementia), reduced isolation, and fostered ongoing contributions to dementia advocacy and care.

Source: Local Government Association (2018) Dementia Post Diagnostic Support. Available at: 22.1 Dementia Support Guide for councils_WEB.pdf (Accessed: 28 August 2025).

Familiarity

Post-diagnostic support programmes like Beyond the Front Door, developed by Halton, Liverpool and Wirral Borough Councils, highlighted that people living with a dementia and their family/carers valued opportunities to reflect on what ‘home’ meant and how this could be maintained as care needs changed. A strong sense of home was associated with continuity of identity, stability, and comfort during times of disruption (Halton, Liverpool and Wirral Borough Councils, 2018).

Case Study: Beyond the Front Door - Dementia and the Meaning of Home

Halton, Liverpool, and Wirral Borough Councils, with the Life Story Network, explored what home means to people living with a dementia and their family/carers, involving around 60 participants including professionals and housing providers.

Interviews and group discussions with people living with a dementia and carers were followed by consultations with housing staff, discharge teams, and commissioners to integrate insights into practice.

Key findings included that:

- Home was described as central to identity, belonging, and wellbeing.
- Emotional connection, personal control, and community ties mattered as much as the physical environment.
- Disruptions such as hospital discharge or relocation were particularly distressing without sensitive planning.

Researchers on the project noted that person-centred dementia care should include meaningful conversations about the significance of home, with housing, health, and social care services working together to respect and preserve a sense of place.

Source: Local Government Association (2018) Dementia Post Diagnostic Support. Available at: 22.1 Dementia Support Guide for councils_WEB.pdf (Accessed: 28 August 2025).

Environmental familiarity also played a role in wellbeing. People living with a dementia were expected to have access to outdoor spaces to support autonomy and wellbeing, as well as everyday opportunities to carry out meaningful household tasks such as ironing or meal planning (Care Inspectorate Scotland, 2017). Research showed that homelike settings and small-scale care environments promoted engagement in daily life activities and enhanced comfort (Woodbridge et al., 2018; D’Cunha et al., 2023). These activities sustained agency and preserved the rhythms of daily life, enabling people to feel at home even in residential care settings.

Cultural and linguistic familiarity were equally important across all care settings. Respecting (where possible) people's preferences to be supported by someone from their own community, who could speak their language and relate culturally, helped maintain trust, identity, and a sense of belonging. The Dementia Alliance for Culture and Ethnicity (2016) urged embedding cultural awareness into dementia care through targeted, grassroots actions. They called for investing in capacity building among community organisations so that support services and information were culturally acceptable and resonated with diverse groups. They also stressed the need for cultural competence training for staff, encouraging reflection on stereotypes, and the co-production of resources tailored to specific cultural needs.

Family involvement was another dimension of familiarity. Roundtable discussions highlighted the principle of shared care, where relatives and families continued to play an active role even after a person moved into a care home. Participants emphasised that relatives often knew the person best and brought valuable knowledge that should not be lost. Sustaining these relationships supported continuity and ensured that the person remained surrounded by familiar people and practices. This aligned with findings from the Angela Project, where post-diagnostic support that included families in education and planning helped preserve identity, autonomy, and social connection for people with young-onset dementia (Stamou et al., 2022).

Case Study: The Angela Project, Young-Onset Dementia

The Angela Project was a UK research study that explored what makes post-diagnostic services effective for people with young-onset dementia and their families (Stamou et al., 2022). Researchers found that specialist services worked best when they offered age-appropriate activities, holistic family support, and continuity of care through link workers.

Examples included boating trips and active peer groups, alongside legal and psychological advice for families. A designated link worker to coordinate care was valued for building long-term, trusting relationships.

Families emphasised the importance of being included not just as carers, but as partners in planning and accessing support. Tailored, family-centred, and continuous provision was seen as essential to meeting the distinct needs of young-onset dementia.

Source: Stamou et al. (2022) 'Helpful post-diagnostic services for young onset dementia: Findings and recommendations from the Angela project', Health & Social Care in the Community, 30(1), pp. 142–153. doi: 10.1111/hsc.13383.

Inclusive environments

Physical environments also shaped how inclusive care settings could be. Research showed that smaller-scale, homelike settings encouraged comfort, participation, and engagement in daily life (Woodbridge et al., 2018; D'Cunha et al., 2023). Spaces designed around familiarity and accessibility, such as safe outdoor areas, quiet rooms, and flexible communal spaces, helped reduce disorientation and supported autonomy. By contrast, institutional or task-oriented environments risked undermining person-led care.

The lived experience roundtables highlighted the importance of creating stimulating and supportive environments for people living with a dementia. There is an opportunity for the sector to continue exploring how to implement inclusive design and person-led environments. CQC could consider gathering practical examples of good practice and sharing these more widely.

Assessments of dementia diagnostic centres in England found several features that made environments difficult for people living with a dementia to navigate, including a lack of dementia-friendly signage, limited use of contrasting colours in corridors and toilets, and disruptive noise from building works (Healthwatch England, 2024). Woodbridge et al. (2018) found that dementia-sensitive design elements such as clear wayfinding systems, contrasting colours, visual cues, and smaller, more navigable layouts, helped residents locate toilets, recognise spaces, and feel more familiar with their surroundings. By contrast, long and complex corridors, poor signage, and insufficient visual landmarks increased confusion and reduced autonomy.

The University of Stirling developed the Environments for Ageing and Dementia Design Assessment Tool (EADDAT) to guide improvements in dementia-friendly environments (Aikman, 2023). EADATT combined practical design principles covering aspects like layout, lighting, signage, acoustics, and outdoor areas, with a digital tool that scored environments and suggested improvements. This approach supported families, staff, and organisations in making buildings more navigable, accessible, and welcoming for people living with a dementia.

Key enablers of good quality care

Staffing and the workforce

Staff confidence and capability were considered key enablers of good quality care. Mitchell and Agnelli (2014) emphasised the importance of staff understanding Kitwood's framework of person-centred care. Without training, staff could unintentionally undermine personhood through malignant social psychology (e.g., infantilisation, ignoring, disempowerment). Positive person-led care, including recognition, negotiation, collaboration, validation, and facilitation, fostered dignity and wellbeing (Mitchell and Agnelli, 2014).

Moenke et al. (2023) also found that dementia training for care home staff supported the introduction of new psychosocial activities, reporting that homes adopted “one-to-one sessions, hand massages, cooking classes, dance and music”. Roundtable participants echoed these findings in relation to care settings beyond residential care. They noted that training to improve staff’s non-verbal communication was central to good quality, person-led care.

One roundtable participant stressed the importance of leadership and culture in shaping everyday care. Drawing on professional experience and personal visits to a care home, they observed that task-oriented approaches often left residents behind as staff moved quickly from one task to the next. In contrast, encouraging staff to “slow down”, spend time with residents, and “just have a cup of coffee”, created moments of comfort, connection, and enjoyment. This cultural shift recognised that the true outcomes of good care were often small moments such as a shared jigsaw puzzle or quiet conversation.

“You want to see staff having that confidence and a tool kit and being able to say, you know, I go in and actually I might try this if that's not working and I can do something else. It's about flexibility rather than a sort of checklist of this is what it looks like.”

Academic, Roundtable 1

Roundtable participants highlighted that such outcomes are difficult to capture through paper-based assessments. For regulators like CQC, this underlined the importance of observing everyday practice directly. For example, noticing whether staff interactions reflect compassion, attentiveness, and respect for each person’s history and individuality. Instead of relying solely on written claims of good quality care for those living with a dementia. It is important for CQC to continue to use existing tools, e.g. the short observational framework for inspection (SOFI), to capture the experiences of people who use services who may not be able to express this for themselves (Care Quality Commission, 2023).

Roundtable discussions also pointed to wider systemic enablers: well-resourced services, stable staffing, and giving staff the time to build relationships were seen as essential to the delivery of person-led care. Without adequate resources, staff were often left “firefighting” and unable to focus on individuals’ needs. Effective leadership was also identified as key to creating cultures where staff felt permitted to prioritise relationships and small, everyday acts of care.

In contrast, roundtable participants highlighted challenges such as staffing ratios and the reliance on agency staff, who might not have known those living with a dementia and their family/carers well. Care documents were sometimes not treated as “living documents,” making it difficult to keep individual needs and preferences current. Providing personalised care in large residential settings was described as particularly challenging for these reasons, despite the aspiration to maintain an individualised approach for every person and a new self-evaluation tool for systems (e.g. Integrated Care Boards) to benchmark themselves against standards of good practice. Developed by NHS England, the Department for Health and Social Care (DHSC), and other partners, the Dementia 100 Pathway Assessment Tool brought together best practice standards for dementia care into one self-assessment framework. The relatively new tool was designed for systems to conduct self-assessments at a place-based level, rather than for use by individual providers. Participants felt it had potential to highlight gaps in local practice and guide service improvement, though noted that it was still early to know how effective it would be in practice.

EADDAT (as discussed above) was also mentioned in the roundtables, as a useful evidence-based framework that enabled the systematic evaluation of how well buildings, homes, and public spaces supported older people and those living with a dementia. It combined a set of design principles covering layout, lighting, signage, acoustics, and outdoor spaces, with a digital assessment tool to score environments and provide recommendations for improvement (Aikman, 2023). This helped families, professionals, and organisations identify practical adaptations that could make settings more accessible and inclusive.

Participants in the roundtables also drew attention to the Dementia Education and Dementia Awareness Tool (DeDAT), developed by Leeds Beckett University, which provided a structured way to evaluate the quality and impact of dementia training. The tool supported organisations in identifying strengths and areas for development in staff training programmes, ensuring that education was both evidence-based and aligned with what worked in practice (Leeds Beckett University, n.d.).

CQC could support improvement by sharing and encouraging the use of emerging frameworks like the Dementia 100 Pathway Assessment Tool, EADDAT, and DeDAT, while continuing to monitor evidence on their value and use.

Evidence gaps

A central challenge lay in measuring delivery and outcomes of person-led care. Participants noted evidence gaps around how best to support good communication with people living with a dementia, alongside wider issues such as emotional support and the role of intimate relationships in care. Tools to capture empowerment and ownership remained limited, with standard satisfaction surveys offering only a partial picture. While observational methods could provide richer insights into the everyday impact of care, they were not consistently applied, and quantitative measures continued to be prioritised.

4 Equalities and human rights

Key findings

- While evidence is relatively limited around what good practice looks like, equalities and human rights were central to good quality care for those living with a dementia and were closely tied to person-led approaches.
- Innovative technologies improved accessibility, reduced language and cultural barriers, and promoted privacy.
- Key enablers were building staff confidence in using digital tools and recruiting a diverse workforce that reflected the local community.
- Research gaps remained around outcomes for those supported, protected characteristics, and Deprivation of Liberty Safeguards (legal procedures to safeguard supported individuals whose liberties are being deprived within care settings, for the person's best interests).

Key features of good quality care

Access

Access to care for those living with a dementia was improved by greater online-facilitated exchanges between different care providers, and between providers and those supported. The 2016 mixed-methods study by Doyle et al. found that remote videoconferencing helped dementia care staff located in remote regions of Australia to access expert peer support from urban care providers. The result was a reduction in stress for both staff and family carers, according to self-reported data from those individuals. Clinicians also reported more confidence in addressing the needs of those supported, which the authors anticipated would lead to broad positive outcomes for those supported and their families (Doyle *et al.*, 2016).

For those living with a dementia and their family/carers, information about dementia care, and support measures for those accessing wider care and support whilst living with a dementia, was made more accessible by providing it online (Dementia Alliance for Culture and Ethnicity, 2015). This included videos on YouTube, community radio shows about dementia, and targeted information campaigns for racially minoritised groups (Dementia Alliance for Culture and Ethnicity, 2015). Good practice in online accessibility included the co-development of online websites and other tools with people with lived experience of dementia, to ensure relevance and usability (Middleton *et al.*, 2023).

CQC could consider sharing best practice across the health and care sector around how information about dementia care and support can be best shared with those living with a dementia and their family/carers. This could include particular reference to ways to support engagement from racially minoritised groups. CQC could also promote gathering more evidence on best practices for support and inclusion for groups where research was more limited on inclusion, including those with disabilities.

Translations and interpretation services also improved accessibility for those living with a dementia and their support networks who were minority language speakers. One study gave the example of quality-assured translated care manuals for family caregivers (Chenowith *et al.*, 2016). The translations helped them reach the community of Chinese carers who were more likely to be reticent in accessing services due to cultural stigma (Chenowith *et al.*, 2016). The Dementia Alliance for Culture and Ethnicity (2015) also noted the importance of having translations for online videos, as well as interpretation when support workers spoke with family carers. Beyond the practical advantages of information-sharing, translations also helped make care for those with a dementia more effective by acknowledging heritage, background and lived experiences.

Three studies shared during the roundtables also identified language as a barrier to those with a dementia and their carers accessing support (James *et al.*, 2024; Jutlla *et al.*, 2024; Parveen, Peltier and Oyebode, 2016). James and colleagues (2024) found that some people in the UK whose first language was not English tended to prefer receiving care from who spoke their primary language. For others in the same study, however, the background of the carer did not affect their perception of care quality.

Several studies highlighted transportation as a key factor in accessibility, with an emphasis on convenient, well-managed transportation options (Diaz *et al.*, 2022; Stamou *et al.*, 2022). People with young-onset dementia in particular preferred care that was accessible and local to the area they lived in (Stamou *et al.*, 2022). While transportation and logistics were relevant concerns for those with physical disabilities and mobility limitations, this group was largely not highlighted in the reviewed literature.

Combining different parts of care in a single setting provided advantages for patients to reduce travel times. For example, an innovative dementia outpatient clinic (‘Comprehensive Memory Center’) utilised a single site for an interprofessional group including professionals from neurology, geriatrics, speech-language pathology, pharmacy and others (Aguirre *et al.*, 2023). This allowed patients to bundle appointments together, meaning they could reduce the number of times they needed to travel (especially important for those who were working) (Aguirre *et al.*, 2023). The designers of the clinic utilised good practice by involving individuals with lived experience with a dementia in the design process through qualitative group sessions to identify what mattered most to them (the findings were long wait times and fragmented care) (Aguirre *et al.*, 2023).

Transportation mattered to clinicians as well, especially those located in remote areas (Doyle *et al*., 2016). In a pilot peer-to-peer videoconferencing intervention in Australia, staff supporting those with a dementia found the electronic communication to substantially reduce their travel time for patient cases and increase time for professional development (Doyle *et al*., 2016).

Sensitivity to identity

The quality of care for those living with a dementia improved when care providers were competent and knowledgeable about the cultural backgrounds of those living with a dementia and their carers (Seetharaman *et al.*, 2022; The King's Fund, 2024). Cultural understanding helped build a trusting care experience. For example, in the Australian videoconferencing intervention described above, increased cultural competence was an additional benefit of the cross-geographic exchange between providers (Doyle *et al*., 2016). Speaking with rural healthcare professionals led urban care staff to report improved understanding and confidence in supporting Aboriginal or Torres Strait Islander patients in their own localities (Doyle *et al.*, 2016).

Participants in the roundtable discussions highlighted food as a key factor that affects people's experience with dementia support, particularly for racially minoritised communities. Informal dementia support groups enticed people to participate by providing culturally relevant foods (mentioned with reference to South Asian communities), while another group cooked hot meals for people from Caribbean backgrounds. During the lived experience roundtable, one participant mentioned that religious preferences for food and clothing should also be considered for those supported in residential care settings to ensure they feel included.

> *"What's really interesting is that they provide food, and that's the … hook that really brings people in, and it's essential to engaging people."*
>
> **Academic, Roundtable 1**

The literature and roundtables highlighted that care for those living with a dementia needed to be acceptable to all participants, meaning those supported considered the intervention appropriate for their daily lives and were open to engagement (Chaudry *et al.*, 2020). Acceptance is enhanced by accounting explicitly for socio-cultural contexts and individual preferences. The previously mentioned videoconferencing intervention was found to be acceptable for members of Aboriginal and Torres Strait Islander communities (Doyle *et al.*, 2016), while a systematic review found acceptability of Montessori-style interventions (see more detail in Chapter 2) across a range of racially minoritised communities (Yan *et al.*, 2022).

For example, researchers successfully adapted Montessori therapy techniques for a care home in Pakistan by replacing images and references predominant in the U.S. and Europe (e.g., pictures of golf) with those more relevant to the Pakistan context (e.g., pictures of cricket) (Chaudry *et al.*, 2020). LGBTQ+ individuals, meanwhile, wanted dementia spaces to utilise music and films that spoke to their identities, as well as avoiding discussions solely around children and grandchildren if that was not their experience (Stinchcombe *et al.*, 2024).

Research was generally limited on supporting individuals with a dementia who identified as lesbian, gay, bisexual, queer or other sexual and/or gender minority (LGBTQ+). Stinchcombe and colleagues' (2024) qualitative analysis of LGBTQ+ people with cognitive impairment, caregivers of those who were LGBTQ+ and caregivers who were LGBTQ+ themselves, described both fears and actual experiences of discrimination in healthcare settings. Language, both verbal and body language, was an important way to show sensitivity to identity. Participants wanted gender identities to be respected by using preferred pronouns, and for same-sex partnerships to be respected by being treated equivalently to heterosexual partnerships.

Community engagement

Local community support groups promoted access to dementia services by providing an accepting space for people to talk about dementia or just to be present with others. This was particularly true for those with protected characteristics, such as sexual orientation and religion, who may feel more comfortable around people living with a dementia who share their identity. The support groups often signpost members to services available in the wider community.

One group highlighted during the expert roundtable was the Greater Manchester Lesbian, Gay, Bisexual, Transgender, and Queer or Questioning (LGBTQ+) Online Dementia Support Group, which meets monthly. The group is described as a “safe and friendly space where you can express yourself and support each other” (Dementia United, n.d.). While this specific group has not been evaluated, other research found that support groups provided moderate positive impacts for socialisation and affirmation for people living with a dementia (Toms *et al.*, 2015). In one qualitative study, LGBTQ+ individuals with a dementia and caregivers, primarily from Canada, expressed desires for such LGBTQ+-supportive networks which they felt were lacking in their local areas (Stinchcombe *et al.*, 2024).

As a further example of good practice, Alzheimer’s Society recently launched a memory café in a mosque in Manchester (Kanczula, 2025). The service provides personalised support for people living with a dementia from South Asian communities (Kanczula, 2025). The case study below elaborates on a similar example.

Case study: Dementia Cafés: Reducing Dementia Stigma in London Borough of Brent

Trained community researchers conducted qualitative ethnographies with 10 local community members in Brent, an ethnically diverse borough, on their daily experiences living with a dementia. The use of local community members to conduct the research helped promote a representative uptake of participants across language, religion and culture.

Among the findings was the fact that people living with a dementia in Brent experienced isolation and loneliness. This was exacerbated for some people from cultural backgrounds where dementia was particularly stigmatised (e.g., through the use of labels such as ‘crazy’).

“Part of the reason he was not able to accept the diagnosis was the cultural stigma and his fear that others would not understand.” – Family carer about participant in Brent

The community launched dementia cafés to create safe places for people living with a dementia and their carers to spend time and/or socialise with others. Community locations include multiple churches and a Gujarati conversation group.

Reactions were positive, such as the experience of one participant who was only able to accept his diagnosis after meeting others at the dementia café. Researchers found that attendees at the café tended to come regularly, and it was often their primary source of support.

Source: Opinion Leader and Community Action on Dementia Brent, 2015

Privacy and dignity

A final consideration with human rights was the tension between safety and privacy. As identified in the roundtables, care providers had a responsibility to keep those supported safe and free from harm. On the other hand, those who participated in the lived experience roundtable placed a high value on their privacy and freedom of movement. Good practice involves a careful and explicit consideration of this balance.

“…some residential homes are quite restrictive in terms of their access…, for their [residents’] own safety at times. But how often is that being reviewed? …What safeguards are really in place for them? [It’s] sometimes a bit difficult.”

Health and social care regulator, Roundtable 2

D’Cunha and colleagues’ (2023) qualitative study within a single care home identified radar technology, as opposed to cameras or frequent bed checks, as an intervention that helped preserve the privacy of residents while also ensuring falls were addressed quickly. The reduction in physically checking residents’ beds at night was highly appreciated by all stakeholders, with staff saving time at night while residents experienced less disruptions. Staff felt the system was also safer due to the immediate alerts in the case of falls, with one nurse making reference to a previous care facility where an unattended fall for several hours led to a death (D’Cunha *et al.*, 2023). Positive risk taking is discussed in Chapter 5.

CQC could encourage the adoption of such technology or others that strike a balance between privacy and safety and share best practice across providers. CQC could also ensure that care providers regularly review restrictive practices as part of assessments, for the purposes of safeguarding freedom.

Key enablers for equalities and human rights

Staff confidence and capability

Building staff confidence and capability was essential for delivering high-quality, equitable care for those living with a dementia. This was particularly the case when integrating digital technologies such as videoconferencing or radar-based fall detection. Training programmes, covered in more depth in the next section, should equip staff with the skills to use these tools effectively. Training was recommended to prepare staff to troubleshoot common challenges such as sound quality and internet connectivity with videoconferencing (D’Cunha *et al.*, 2023), and false alarms with falls-detection technology (Doyle *et al.*, 2016).

The consideration of digital skills extended to those living with a dementia and their carers. A systematic review reported that using paper documents improved access for some patients for whom digital tools would be less appropriate (Aworinde *et al.*, 2024). Those with young onset dementia (defined as dementia in someone under the age of 65) preferred in-person activities over online ones due to the greater social connection (something more often lacking for this group) (Stamou *et al.*, 2022).

> *“I could look on the internet and look at a website that lets you chat with other people, but it’s not the same as talking to somebody and meeting the other person with dementia as well. That’s very important, I like meeting others.”*
>
> **Person with young-onset dementia (cited in Stamou *et al.*, 2022)**

Beyond training, support for those living with a dementia and their carers benefitted from a representative workforce that reflected the demographics of local communities (Weiss *et al.*, 2020). This was a key enabler for culturally sensitive and inclusive care. Recruitment to roles supporting those living with a dementia and their carers should facilitate diversity and inclusion, potentially through the use of targeted recruitment strategies - although there was a gap in the actual development of such strategies (Weiss *et al.*, 2020).

To support services being well resourced and diverse, CQC should continue to collaborate with relevant sector organisations (e.g. Skills for Care). This could include supporting relevant campaigns and work to understand the needs of the sector in terms of staffing diversity. This will support providers to take the steps to provide good quality care that meets people's needs and preferences.

Community connections

Roundtable participants pointed to several conditions that allow strong community connections to flourish. These included collaboration across local partners (e.g. councils, voluntary organisations, and statutory services), co-design with those living with a dementia and their families, and the involvement of diverse volunteers to build trust and inclusivity. Ensuring that dementia was understood as "everybody's business" was also seen as essential, with shared responsibility across community stakeholders helping to reduce stigma and foster belonging.

Resources and infrastructure were further highlighted as enablers. Dedicated spaces, such as community hubs or dementia-friendly venues, created welcoming environments for participation. Equally, time and resources for staff and volunteers were seen as critical enablers. When staff had sufficient time and capacity, they could focus on building and sustaining relationships rather than firefighting immediate pressures. Leadership and coordination at a local level supported sustainability, ensuring initiatives were not dependent on a single organisation or short-term project.

Creative and arts-based activities were described as effective vehicles for community connection, but their success depended on these underlying enablers, particularly co-design, continuity of funding, and recognition of people living with a dementia as active contributors. Young, Camic, and Tischler (2016) found that arts-based programmes were most impactful when embedded within wider community networks, supporting communication, social contact, and active engagement.

“It really dawned on me last year when somebody came into the shed [a local hub for those with dementia] and said, ‘oh, you've got music playing’. And I said, it's all the playlists of all the people who come to the shed, it was all their playlists coming together for that particular day. It changes every day depending on the person who comes to the shed. You just think it's part of what you do, isn't it?"

Practice and innovation lead, key sector body, Roundtable 1

Evidence gaps

Although this section pulled out the evidence where it existed, there were broad evidence gaps on the subjects of equalities and human rights for those living with a dementia. Several of the most recent studies identified this as a wider concern for the literature (Aworinde *et al.*, 2024; Diaz *et al.*, 2022; Janes *et al.*, 2025; Panagiotidou *et al.*, 2024). This included gaps in research on outcomes for those living with a dementia and their carers, good practices for those with protected characteristics (including those who are LGBTQ+ and those with physical and learning disabilities), and the role of intersectionality across these themes.

A particular research gap was found in relation to Deprivation of Liberty Safeguards (DoLS). These are legal protections in England and Wales for those who lack decision-making capacity, ensuring that any restrictions on their liberty are assessed and in their best interests (Social Care Institute for Excellence, 2022). DoLS were an area of interest for CQC which did not come out in the examined literature. This includes a lack of literature on the impact of locked rooms in care homes and hospitals, although sector experts and people with lived experience highlighted in the roundtables that they found strong restrictions on movement to have negative impact on care.

One woman in the lived experience roundtable described a negative care home experience for her father, where staff placed a table in front of him so he could not wander (walk around). The family caregiver compared this with a different care home who let her father move around as he wanted, viewing this as more akin to a home environment where people can walk around freely. While this might have increased risks of falling or other risks, one regulator in the roundtables noted that care residents do not want to be monitored at all times and value independence. While anecdotes provide useful steering, further research on this balance between safety and protection of freedoms (including freedom of movement) would be beneficial.

Equity and inclusion also required greater attention. Evidence was relatively sparse on the experiences of racially minoritised communities, LGBTQ+ people, those in rural settings, or people with rare dementias. Young-onset dementia (dementia symptoms in people under the age of 65) presented distinctive challenges, as existing services often did not align with the needs of younger people and their families. Roundtable participants highlighted the importance of developing more tailored pathways and collecting dedicated data to address these gaps.

5 Staffing and training

Key findings

- Evidence showed that good quality dementia care relied on staff having both general and person-specific dementia knowledge, with practical communication and behavioural support skills being especially valued.
- Dementia training for all staff - including those in non-care roles - was essential for building core competencies and ensuring care is tailored to individual needs. However, current standards and provision were inconsistent across the UK and internationally.
- Training in communication strategies had shown improvements in staff confidence and, more indirectly, for care quality. Peer-led, multidisciplinary training approaches were good practice, including coaching and mentoring.
- Key enablers for effective training include sufficient staff capacity, fair compensation for training time, peer support, and a representative workforce.
- There are still gaps in research on the direct impact of training on outcomes for those living with a dementia and their carers, and the long-term effectiveness of training interventions, highlighting the need for further study.

Key features of good quality care

National training standards

There is currently no legal requirement for all health and care staff to undertake dementia training in England. However, providers are required under the 'Health and Social Care Act 2008 (Regulated Activities) Regulations 2014: Regulation 18' to ensure that staff are suitably qualified, trained and skilled to 'meet the needs of the people using the service' (Care Quality Commission, 2025a), which applies to services for people living with a dementia. Despite an increased profile regarding the importance of dementia training and increased advocacy for mandated training for the social care workforce – the standards of education vary substantially, with improvements relying most often on aspiration rather than government or regulatory instruction. The lack of a national standard adds to research gaps as there is no definitive information on what training is available and how to measure impact on staff.

Although not mentioned in the reviewed literature on dementia, participants in the roundtables suggested that support for those living with a dementia could learn from mandatory training requirements for learning disability and autism, mandated under the Health and Care Act 2022 for all CQC-registered service providers (Care Quality Commission, 2025b).

Although considerable attempts were made to create standardised education frameworks and induction practices for social and health care workers, evidence suggested that much of the training currently provided was not evidenced based or of high quality. Current competency in dementia care was assessed by several studies as being low in the UK (Heward *et al.*, 2021; Robinson *et al.*, 2025), as well as Australia (Goh *et al.*, 2022), Canada (Moody *et al.*, 2024), and globally (van der Weide *et al.*, 2023). This was marked by low knowledge about dementia generally, and low skills in supporting people living with a dementia (Smith *et al.*, 2019). A report from Alzheimer's Society (2024) noted that only 29% of care staff in England had any kind of dementia training.

Dementia training was recommended by key sector organisations, for example in National Institute for Health and Care Excellence (NICE) guidance, which said *"care providers should provide all staff with training in person-centred and outcome- focused care for people living with dementia."* (NICE, 2018). The Skills for Care workforce strategy published in July 2025 also stated that all care staff should undertake training mapped to the Dementia Training Standards Framework (Skill for Care, 2025).

Several international examples demonstrated good practice in establishing national training standards. In Japan, the Comprehensive Strategy to Accelerate Dementia Measures provided a coordinated framework for dementia care and training (Urashima *et al.*, 2022). In Scotland, the 'Caring for Smiles' programme offered a national oral health promotion initiative specifically targeting care homes, as identified in a report on people living with a dementia in care homes (Care Inspectorate Scotland, 2017). In Ireland, the Cuimhe Strategy adopted a whole-community approach to dementia, encompassing awareness, training, and support (The Dementia Alliance for Culture and Ethnicity, 2016).

While dementia training was available through particular accredited bodies, such as Dementia Australia, it had not yet been mandated, leaving provision inconsistent across settings (Brazil *et al.*, 2018; Goh *et al.*, 2022; Aworinde *et al.*, 2024). This lack of standardisation underlined the importance of integrating evidence-based, accessible, and inclusive training, aligned with national frameworks. One good example was Scotland's 'Promoting Excellence' framework, which identified the 'essential knowledge and skills that staff need to support people living with a dementia' (Care Inspectorate Scotland, 2017). Using the Promoting Excellence framework*,* care inspectors in Scotland paid particular attention to care home staff training on dementia, including whether the training provided practical skills (e.g., managing distress). Evidence on the direct impacts of these frameworks and strategies was limited and not directly addressed within the studies in this review.

CQC should continue to work with other sector organisations around the requirement for dementia training for health and care professionals. This could include ensuring that training quantity and quality is monitored as part of provider assessments.

Staff capability

The literature recommended that all those who work with people living with a dementia and their carers have dementia-relevant skills and knowledge (van der Weide *et al.*, 2023). As a starting point, staff needed to understand the typical symptoms and needs of people living with a dementia, such as falls, incontinence, delirium, and progressive cognitive impairment (Jones *et al.*, 2022). This was of equal importance for those who did not work regularly or predominantly with people living with a dementia, such as hospital staff, as for those working frequently with those with dementia (Jones *et al.*, 2022; Moody *et al.*, 2024; Goh *et al.*, 2022). Relatedly, several studies advocated for dementia training and competency amongst those in the broader sphere of health and care, such as those working within care settings in catering, administration or management, domestic support and other roles (Jones *et al.*, 2022; Sampson *et al.*, 2017). While not directly providing care, those staff interacted with persons with a dementia at times and contributed to the overall environment of the care setting.

Alongside general knowledge, those working with people living with a dementia needed to understand how to treat each person as an individual (Goh *et al.*, 2022). Staff needed to not make assumptions but instead pay attention to the person before them (Goh *et al.*, 2022). This theme was explained in depth in Chapter 2 on person-led care, and was picked up in the expert roundtable, as the quote below exemplifies.

> *"… every single person that supports somebody with dementia should be looking at what their [own] skill set needs. Now, people would like it to be like, "Here's your menu that you need to achieve if you're in a particular role." But it's a bit more complex because it's like, who is it that you're supporting within that role? But people should be at skilled level, at least skilled level when they're working within care homes."*
>
> **Health and social care regulator, Roundtable 2**

Staff training was connected to care quality in several ways, as elaborated in Alzheimer's Society's landmark report, *Because We're Human Too* (2024). As a starting point, staff gained more understanding of the needs associated with dementia, improving their ability to meet those needs. Staff also improved job satisfaction and reduce burnout due to less confusion and agitation in those they support (Alzheimer's Society, 2024).

Innovative approaches to hospital care delivery demonstrated the value of all staff being specifically trained and attuned to the needs of people living with a dementia, with added value from greater exchange between teams. Enhanced Dementia Care Units, for example, trained multidisciplinary staff teams in the behavioural and psychological symptoms of dementia and delirium (Jones *et al.*, 2022). These units were associated with improved documentation of treatment decisions and reduced hospital readmissions (Chenoweth *et al.,* 2015; Jones *et al.,* 2022).

Similarly, models promoted coordination across providers, such as the Rapid Assessment Interface and Discharge (RAID) approach, which encouraged liaisons between psychiatry and emergency room departments. The RAID model not only reduced length of admission by about 7.5 days per admission but also promoted continuity and higher-quality dementia-specific care (Jones *et al.,* 2022). These organisational and structural innovations highlighted the importance of embedding specialised dementia expertise within care settings, complementing individual staff competencies.

Person-led training approaches such as the WHELD intervention, which trained staff to create tailored social activities (see Chapter 2), were linked to direct benefits in care outcomes. Following staff training with WHELD, care home residents experienced a 2.5-point increase in a range of quality-of-life measures (e.g. positive emotional state, participating in daily activities), alongside reduced stress for staff and family carers (Ballard *et al.,* 2018). Observational evidence also showed that the engagement of those living with a dementia in activities improved, particularly where staff had received virtual coaching compared with e-learning alone (McDermid *et al.,* 2022).

Need for practical training

Staff desired practical and applied guidance and training, particularly around communication skills and ways of meeting needs around distress and emotions (Alzheimer's Society, 2024). Training was particularly sought in relation to direct communication with people living with a dementia, as well as in recognising and interpreting body language that could signal unmet needs (Handley, Bunn and Goodman, 2017). Home care workers further highlighted the importance of learning how to respond to distress and manage someone's unmet needs (Goh *et al*., 2022).

Family carers in the lived experience roundtable also noted the importance of dementia training for both staff and for family carers themselves. They described training as a relevant area of concern for CQC, requesting greater scrutiny by CQC on staff training (mentioned in relation to hospitals and care homes). The literature further documented a desire in family carers to learn more about coping strategies for themselves to use when supporting loved ones experiencing distress, emotions or unmet needs that the caregiver may find challenging (Kishita *et al*., 2018).

Evidence suggested that structured communication interventions enhanced staff preparedness and self-efficacy in dementia care. See example below.

Case study: MESSAGE Communication Strategies in Dementia for Care Staff Training

‘MESSAGE Communication Strategies’ is a multimedia training programme that teaches practical communication approaches for staff to use with people living with a dementia. The programme considers the needs of people living with a dementia, such as simple language where appropriate, as well as non-verbal communication (e.g., body language).

The acronym stands for:

M: Maximise attention

E: watch Expression and body language

S: keep it Simple

S: Support the conversation

A: Assist with visual Aids

G: Get their message

E: Encourage and Engage in communication

The authors conducted a randomised pre-test-post-test trial of the training, using two community aged care centres in Australia. Staff received a 60-minute training with presentation of a training DVD and follow-up discussion which was facilitated by a Speech Pathologist. Participants received a booklet with the strategies written out, and with encouragement to practice the teaching examples for two weeks afterwards.

Findings:

- Significantly higher scores on measures of self-efficacy (staff confidence in their ability to handle communication scenarios).
- Knowledge of communication strategies increased after training, with the knowledge holding up after three months.
- 100% of staff used the strategies, with 78.6% doing so frequently.

Source: Conway and Chenery, 2016

The Dementia Education and Learning Through Simulation 2 (DEALTS2S) intervention, a simulation-based training programme that promoted confidence and empathy in dementia care, was also associated with increases in dementia knowledge among participants (Heward *et al.*, 2021). Following a one-day workshop on DEALTS2S with ward managers and nurse specialists in the UK, researchers reported a 44% increase in staff communication skills and knowledge of person-led care between pre and post-test assessments (Heward *et al.*, 2021).

Communication skills also brought additional benefits for care quality by helping to reduce stress for staff. One study that provided whole-institution training on communication skills when working with people living with a dementia found statistically significant increases in job satisfaction for both clinical and non-clinical staff (Murray *et al.*, 2019). Alzheimer’s

Society (2024) also highlighted data from Skills for Care which found that social care staff with regular training (not necessarily about dementia) had lower turnover rates compared to peers without regular training (31.6% vs 40.6%, respectively). At the same time, Alzheimer's Society (2024) also noted that it can be difficult to attribute training directly to job outcomes, due to a number of other factors such as compensation and workforce culture that can affect the job experience. This may contribute to the limited literature available on the effects of training on burnout and job satisfaction and longer-term effects on care quality (discussed further below).

Value of dementia-specific roles

The introduction of dedicated roles such as dementia-specific Palliative Care Planning Coordinators (registered nurses trained in palliative care) demonstrated the effectiveness of embedding expertise within teams (Luckett et al., 2017). Palliative Care Planning Coordinators were able to instruct other healthcare professional staff on best practices in dementia palliative care, including talking more openly about death and dying, and speaking with the person supported and their family to understand what matters most to them. Palliative Care Planning Coordinators were key players not only for their work in facilitating case conferences but also their role as trainers and educators for other healthcare professionals (Luckett et al., 2017).

Non-specialised staff such as nurses or even community members could also be trained to be 'dementia champions', meaning they advocated for those living with a dementia and helped with case management by connecting those living with a dementia with relevant support in the community (Jones et al., 2022; Local Government Association, 2018). Evidence on the specific impacts and effectiveness of dementia champions was scarce in the literature.

Key enablers of good practice

Staff capacity

Sufficient staff capacity is necessary to enable both participation in, and implementation of, dementia-related training (Backhouse *et al.*, 2017; Brazil *et al.*, 2018). Staff capacity includes having sufficient numbers of staff on shift as well as staff having manageable workload demands throughout the day (Handley, Bunn and Goodman, 2017; Seetharaman *et al.*, 2022). Challenges in achieving this are reflective of broader concerns in the social care sector, including high turnover, workforce shortages and difficulties with recruitment (Smith *et al.*, 2023).

Participants in the lived experience group acknowledged the time and workload demands on those who work with people living with a dementia and wanted to see more support in place. This included well-being support, better pay, and broader societal recognition and valuing of the work done. One carer noted it was not always easy to be patient and kind when one has a 'million' things to do.

Participants in the lived experience roundtable also reported a perception that training may be frequently completed on staffs' own time, without compensation. They felt that in order for training to be good quality and embedded effectively, staff needed to be fully supported in their training. Crucially, organisations needed to create the conditions for training to be meaningful, including protected time for staff to participate, planned cover, and opportunities for reflection to embed learning into practice (Handley *et al*., 2017).

Implementation and methods of training

Training implementation benefitted from considering the capacity of staff, such as prioritising afternoon sessions due to the busier nature of morning shifts (Magee *et al*, 2017). The reviewed studies tended towards longer training sessions, ranging from multiple 25-minute sessions (McDermid *et al.*, 2022), up to a 4-day residential training programme on Dementia Care Mapping, a tool for staff to observe those they support more closely and consider if their care needs are being met (Griffiths *et al.*, 2021). Participants noted that although Dementia Care Mapping offered rich insights, the intervention required time and repeated practice before skills could be effectively applied in care settings (Griffiths *et al*., 2021).

The roundtable discussions also highlighted feedback directly from the sector that health and care staff want short and accessible training materials, such as 5–10-minute videos or podcasts. These formats could be more easily fitted into busy schedules. One participant highlighted an app called 'CLEAR Dementia Care © App' that provided quick-to-access guides on handling different situations in dementia care. At the time of writing, there was no evidence on the effectiveness of this app.

Furthermore, good training programmes had defined objectives and measurable outcomes, with managers monitoring progress via staff observations, meetings, and supervision to resolve daily practice issues (Moenke *et al.,* 2023). Indeed, a hallmark of good training was the presence of impact evaluations, to assess whether objectives were met in practice. While some studies used observations to evaluate the impacts of training, standardised evaluation tools were also available. For example, the Dementia Training Design and Delivery Audit Tool (DeTDAT) was developed to provide a comprehensive, evidence-based checklist of good practices that contribute to effective dementia training (Surr *et al.*, 2018). These included aspects discussed in this chapter, such as the training being tailored for the specific service setting, utilising national frameworks where possible, learners referring to their own practice for examples, learners having dedicated time to engage in the training, and including interactive activities (Surr *et al.*, 2018). Leaders had an important role in creating and supporting a reflective, learning-focused environment, as emphasised by Alzheimer's Society (2024). The role of leaders is explored further in the next chapter.

Peer training methods

Another enabler of effective training was the train-the-trainer model, where some staff received more in-depth training and trained their peers (Sampson *et al.*, 2017). For example, this model allowed for implementation across an entire hospital, in part due to the lower demands on the trainees (although higher on the trainers) (Sampson *et al.*, 2017). In one example, staff who had been trained subsequently took on the role of training their colleagues within the same setting. This enhanced the confidence of both trainers and participants in providing dementia care, as training could be made more specific to the setting. Staff in Sampson *et al.* (2017) reported a seven-point increase in their sense of competency following a train-the-trainer programme. As a downside, turnover was a particular concern for interventions that relied on a small number of train-the-trainer staff members (Griffiths *et al.*, 2021).

Evidence gaps

Despite the growing number of training interventions and evidence of improvements in staff knowledge, confidence, and application of person-led strategies, gaps remained in the literature. Participants in the expert roundtable discussions acknowledged these evidence gaps, attributing them at least in part to the less tangible nature of the skills developed in the training sessions.

Relatedly, most studies on training primarily measured indirect outcomes, such as increases in staff awareness, communication skills, or self-efficacy, rather than direct effects on the experiences or quality of life of people living with a dementia (Conway *et al.,* 2016; Sampson *et al.,* 2017; Smith *et al.,* 2020). Only a few studies reported direct care improvements, and these were generally based on observational or mixed-methods evidence rather than robust quantitative evaluation.

"It is very difficult to say that training staff have received has led directly to changes in the quality of care provided. Making this connection is often too big a step and often the right evidence is not collected to do so."

Academic, Roundtable 1

CQC could consider reviewing its approach to assessing training outcomes, aiming to balance the need for meaningful improvements in care with reasonable methods and expectations in evaluation.

6 Leadership and culture

Key findings

- The literature review found that leadership underpins all aspects of good dementia care, shaping culture, person-led care, training, and collaboration.
- Effective leadership in care for those with a dementia relied on supportive, well-trained leaders who held person-led values, used respectful communication, and fostered a positive culture that motivated staff and prioritised dignity and autonomy.
- Sustaining culture change over time was difficult to evaluate, frameworks were inconsistently applied, and limited investment in staff empowerment and leadership capacity constrained progress.

Key features of good quality care

Quality assurance

Quality assurance was widely regarded as important in dementia care, with structured frameworks and audit tools being used to standardise care and demonstrate effectiveness. These approaches provided consistent assessment across health and social care, ensuring needs were met (Brazil *et al.*, 2018; Royston *et al.*, 2020). Quality assurance tools, such as audits, performance reviews, and feedback tools, created benchmarks for good practice, helped monitor care delivery, highlighted areas for improvement, and ensured accountability to people living with a dementia and their families.

There were innovative frameworks for residential care settings, such as the TRaCAd (Thematic Resident and Care Audit for dementia) audit tool which required staff to score 100% on 300 questions about residents to become dementia care framework accredited (Royston *et al.*, 2020). Royston *et al.* (2016) found that the audit helped care staff to improve quality of life for people living with a dementia in care homes, particularly through facilitating care experiences which focused on broader aspects of holistic care such as a person's psychological, social and spiritual needs.

Best practice also required ongoing staff training and evaluation to maintain alignment with person-led principles (Seetharam *et al.*, 2022). Regular performance reviews, training evaluations, and team assessments were essential. Periodic team assessments, such as the Team Fitness Test (a 25-item questionnaire used to assess team functioning, effectiveness, and satisfaction), along with satisfaction surveys for those living with a dementia and their carers, provided additional evaluation and quality assurance of staff training and care delivery (Aguirre *et al.*, 2023).

Feedback and accountability mechanisms were also considered best practice as they enhanced transparency and drove continuous improvement. A good practice example was provided by Royston *et al.* (2022), who found effective use of anonymous, real-time digital platforms for those living with a dementia, families, and staff to provide live feedback. This approach not only allowed services to adapt care in response to ongoing input but also helped ensure that person-led care and family engagement remained central to ongoing delivery of care.

Positive risk-taking

The literature consistently emphasised the need for dementia care to move from risk-averse approaches towards balanced, positive risk-taking. This approach required weighing potential hazards against benefits such as independence, dignity, and meaningful engagement. The idea was that this supported services to replace restrictive practices with strategies that empowered those supported, while maintaining appropriate safeguards to protect safety and wellbeing (Seetharam *et al.*, 2022; Behram *et al.*, 2017; Handley *et al.*, 2017).

Achieving this required rethinking how ‘safety’ and ‘risk’ were defined in dementia care. The concept of ‘dignity of risk’ highlighted that accepting some level of risk was important for maintaining a person’s independence and dignity, rather than always choosing the most cautious approach (Behrman *et al.*, 2017). Behrman found that both caregivers and health and care staff recognised that some risk was necessary to enhance autonomy, though approaches differed. Staff prioritised structured assessments and policies, while caregivers more often relied on pragmatic, informal strategies (Behrman *et al.*, 2017). Best practice involved collaborative risk management, with responsibility shared to balance autonomy and safety. An example of this shared during the roundtables was provided below.

Case study: *Sailability*

The Whitefriars Sailing Club in the Cotswold Water Park welcomed the Forget Me Not Centre – a support group for people with an early onset dementia – from Swindon each week for six months, as part of the Sailability programme. The initiative enabled people living with a dementia to enjoy sailing safely, with boats adapted for stability, supportive seating, and assistive controls. Large accessible pontoons and secure hoists allowed easy access for those with mobility challenges, while experienced volunteers supported participants toward independent or group sailing.

Sailability showcased positive risk-taking and multi-organisational collaboration, involving the club, Alzheimer's Society, Sport England, and volunteer networks including Dementia Friends. Volunteers facilitated social connections, skill-building, and confidence, helping participants engage in meaningful, person-led activities. The programme demonstrated how tailored support, accessible environments, and partnerships can expand opportunities for people living with a dementia to participate safely in community activities and pursue new experiences.

Source: The Whitefriars Sailing Club, 2019 (described during Roundtable 1)

Leadership was critical to fostering positive risk-taking, as leaders set the tone for balancing autonomy and safety. They provided guidance, accessible expertise, and practical strategies such as wristbands or colour-coded clothing to monitor those supported while allowing independence (Handley *et al.*, 2017). A key suggestion from roundtables, supported by the literature, was that leaders had to be brave and have confidence, alongside an understanding of their responsibilities and organisational structures to better support positive risk-taking (Jones *et al.*, 2022). In addition, they clarified staff responsibilities to avoid confusion around roles and responsibilities and supported staff in making safe, tailored decisions that enabled autonomy (Stott *et al.*, 2017). Without leadership support, staff felt unable to take calculated risks, particularly during busy shifts or complex care situations (Chenoweth *et al.*, 2015; Handley *et al.*, 2017).

“What’s required of leaders and organisations, to enable risk enablement, is a high level of bravery and confidence of what the rules are of good dementia care… it requires a leader to know absolutely how the system works, what our responsibilities are and be able to justify those decisions because it can be scary from an organisational and commercial point of view… it’s also about those things being held at a leadership level and not pushed down to the team on duty at the time because you’re asking a lot.”

Academic, Roundtable 1

Best practice in care for those living with a dementia should promote positive risk taking through shared decision-making, ensuring autonomy and dignity remain central to care. Consideration will need to be given to how CQC’s assessment approach balances safety, with the ability of staff and leaders to take positive risks.

Flexibility in work practices

Effective leaders promoted flexibility in workplace practices to enhance person-led care. They empowered staff to take initiative and find solutions that met the personal needs of people living with a dementia (Moenke *et al.*, 2023). Crucially, this required moving away from a task-based culture, where staff followed routines rigidly without the resources to implement person-led care principles (Care Inspectorate Scotland, 2017).

While training provided important knowledge and skills, it was insufficient if the care environment remained task focused. Leaders therefore needed to embed person-led values into systems of care, ensuring staff adapted routines and interventions to individual needs, rather than completing tasks (Handley *et al.*, 2017). This shift was supported when leaders built flexibility into daily operations, enabling staff to personalise care in real time rather than adhere to rigid schedules. For example, approaches like Circles of Support (a group of people who helped the person with a dementia think about how they could maintain or enhance their enjoyment of life) allowed staff to co-design routines and activities based on each person’s current preferences (The Dementia Alliance for Culture and Ethnicity, 2016). This supported promotion of meaningful engagement over standardised task completion.

Flexibility also allowed staff to respond to the emotional state and ‘be with’ the people they were supporting in their reality, improving wellbeing and engagement (Handley *et al.*, 2017). By supporting staff to personalise care - from flexible dining arrangements to quiet spaces for reflection - leaders created an environment where autonomy, dignity, and preferences were prioritised (Seetharam *et al.*, 2022; Chenoweth *et al.*, 2015). Staff also reported greater satisfaction and a sense of purpose when they were empowered to be flexible in their approach to care delivery (Goh *et al.*, 2022).

Bottom-up leadership models (a leadership style where decision-making, innovation, and ideas originated from lower-level employees and teams, with senior management acting as support to implement these initiatives) further reinforced this flexible, person-led approach by shifting away from directive, top-down management structures. When frontline staff were empowered to make day-to-day decisions, supported rather than controlled by senior leaders, they were more able to respond to the unique needs of each individual (Seetharam *et al.*, 2022).

> *"What might work for that person one day, may not work the next. You don't want to be seeing a checklist of 'if staff do this, it's good practice', you want to see staff having that confidence and a tool kit and being able to say, I might try this, if that's not working, I can do something else. Again, it's about flexibility, rather than a checklist… I think that's founded on staff having a good knowledge base, a toolkit, and then confidence and the support to put it in place and not feel they're going to get blamed, I think that's so important for the culture."*
>
> **Academic, Roundtable 1**

Consideration will need to be given to how CQC's assessment approach recognises and encourages the need for flexibility. Learning could be taken from health and care regulators in other UK nations around the use of observations to determine good quality, flexible care, as well as staff empowerment and skill to provide this.

Importance of joined-up, multi-agency partnership working

As the needs of people living with a dementia spanned medical, psychological, and social domains, no single service could provide comprehensive support. Multi-agency collaboration helped to address fragmentation in health and care systems, improve coordination, and deliver more tailored, person-led approaches. Importantly, effective partnership working not only required organisational collaboration but also the meaningful inclusion of people living with a dementia and their carers in the design and delivery of services (Aworinde *et al.*, 2024).

Dementia care networks were a model of partnership working, formalising multi-professional collaboration among GPs, specialists, nurses, therapists, local authorities, and community services. In Germany, dementia networks were used to address fragmentation by linking diverse services and stakeholders to provide tailored care and information (Gräske *et al.*, 2018). Their success stemmed from adaptability, with networks responding to local needs. Some prioritised direct care delivery and streamlined service navigation, while others focused on community education or carer support (Gräske *et al.*, 2018). Central to their effectiveness was building trust among stakeholders and fostering a shared commitment to person-led outcomes. Practices such as care team huddles, interdisciplinary case conferences, and lived experience ‘councils’ also strengthened collaboration by ensuring both professional and family perspectives shaped care (Seetharam *et al.*, 2022).

There is a clear need to consider how regulation can better recognise and promote practices that reduce unnecessary time spent in acute care settings, including hospitals, and support people living with a dementia to return home safely. This includes attention to how transitions are managed between settings, the role of staff training and communication, and the creation of environments that feel familiar and reduce distress.

“There's some things that are helpful to highlight… there's things around how we support those transitions from one space to another and how much you can create an element of continuity. This definitely needs more consideration.”

Academic, Roundtable 2

Local examples in England also reinforced these findings - see example from Doncaster below.

Case study: The Doncaster Admiral Nurse Service

The Doncaster Admiral Nurse Service was piloted to provide multi-disciplinary support for people living with a dementia and their families, offering a single point of contact post-diagnosis. Co-designed by Making Space and Dementia UK in partnership with the Clinical Commissioning Group (now the Integrated Care System) and Doncaster Council, the service linked families to community resources, built resilience, and coordinated care. Delivered by Admiral Nurses and Dementia Advisers, it supported discharge planning, ongoing case management, and care coordination through three levels: holding, maintaining, and caring.

Personal outcomes included:

- people have personal choice and control or influence over decisions about themselves;
- people know that services are designed around their needs;
- people have support that helps them live their life;
- people have the knowledge and know-how to get what they need;
- people live in an enabling and supportive environment where they feel valued and understood;
- people have a sense of belonging, of being a valued part of family, community and civic life.

Source: Doncaster Metropolitan Borough Council - The Doncaster Admiral Nurse Service (Local Government Association, 2018)

Local leadership and community-based partnership

Local leadership and community-based partnerships were seen as essential in embedding best practice dementia care. While formal multi-agency integration brought together statutory services to reduce fragmentation, localised approaches differed in that they drew strength from grassroots engagement and the mobilisation of informal networks, advocacy groups, and local organisations. This helped to build trust and reduce stigma within communities (The King’s Fund, 2024).

Local authorities and ICSs also played a key role by convening collaborative forums in partnership with community organisations, creating spaces where people living with a dementia, carers, service providers, and community representatives could collectively identify and shape local priorities (Local Government Association, 2018; Panagiotidou *et al.*, 2024). These partnerships worked effectively because they grounded dementia care in local contexts, leading to reduced stigma and support that was not only accessible but also culturally appropriate and reflective of community values. Two examples of good practice were provided below.

Case study: Worcester City Council's Dementia Dwelling Grant

The Dementia Dwelling Grant (DDG), led by Worcester City Council, was a multi-agency initiative that supported people living with a dementia to live independently at home. Funded through the Better Care Fund (a partnership between NHS England, the Ministry of Housing, Communities and Local Government, the Department of Health and Social Care and the Local Government Association), the scheme provided non-means-tested grants of up to £750 for home adaptations such as dementia clocks, touch lighting, contrasting toilet seats, and identification stickers.

The programme was co-designed by a task group spanning six local authorities, pooling technical expertise from housing teams with knowledge from health, social care, and voluntary organisations. This ensured adaptations were both safe and tailored to the daily living preferences of those living with a dementia. Oversight was provided by a clinical engagement group, including occupational therapists, housing officers, the University of Worcester's Association for Dementia Studies, and Age UK Dementia Advice Service. Referrals came from GPs, community mental health teams, and early intervention services, with Age UK supporting households to claim grants and access advice.

Source: Worcester City Council's Dementia Dwelling Grant (Local Government Association, 2018)

Case study: Bracknell Forest Council Dementia Forum

Bracknell Forest Dementia Forum is a recurring multi-agency meeting hosted by the Local Authority. It is held every six months and attended by c. 80-90 people. The aim is to use the power of collaborative local expertise to co-design new and improved dementia services. Stakeholders include people living with a dementia, carers, the local authority, members of the local Dementia Actional Alliance (DAA), health and social care practitioners, local commissioners, GP dementia leads, hospital dementia leads, care homes, home care agencies, community groups (including faith groups), advocacy services and local health and social care college students.

The one-day sessions combine service updates, networking, and facilitated discussions where participants identify strengths, challenges, and priorities for improvement. Feedback is reviewed by the Council's Dementia Partnership Board and directly shapes changes such as clearer care pathway information. By valuing lived experience and fostering collaboration across sectors, the forum has built stronger community awareness, more person-led services, and responsive improvements in dementia care.

Source: Bracknell Forest Council Dementia Forum supporting local stakeholders to connect and co-design dementia services (Local Government Association, 2018).

Key enablers of good quality care

Key characteristics of effective leadership

Key enablers of good quality leadership and culture in dementia care included leaders acting as supportive role models, promoting diversity, and being well trained for their roles. As discussed at the roundtables, leadership development was prioritised, ensuring individuals were upskilled before assuming managerial responsibilities, as clinical excellence alone did not guarantee effective leadership. Evidence showed that leaders who completed training like *My Home Life* - a UK programme focused on person-led, evidence-based leadership - could effectively improve their skills and enhance staff morale, motivation, and the overall culture of care (Moenke *et al.*, 2023).

Effective leaders set the example for communication approaches. It was important that they encouraged the use of clear, simple, and respectful communication, avoiding jargon, euphemisms, or demeaning labels, and instead adopted dignity-affirming language that supported autonomy (Conway *et al.*, 2016; Moenke *et al.*, 2023; Aworinde *et al.*, 2024; The King's Fund, 2024; Janes *et al.*, 2025). Communication moved away from task-focused language and instead used phrasing that empowered people living with a dementia - for example, in a residential setting staff asked, "shall we go to your room together?" rather than "I am taking you to your room" (Care Inspectorate Scotland, 2017). By embodying these practices, leaders not only enhanced staff confidence and motivation but also reinforced a culture where dignity, respect, and personhood were prioritised in every interaction.

In addition to knowledge of regulation, CQC teams should have a strong understanding of the available best-practice guidance on leadership, so that they can signpost leaders to relevant sources of improvement support both for services as a whole but also for their leadership skills when care falls short of expected standards.

Partnership working

Integrated, multi-disciplinary collaboration was widely recognised as best practice in dementia care. Effective support relied on coordination across health, social care, housing, community, and voluntary sectors, with regular cross-disciplinary meetings, case conferences, and joint decision-making to ensure consistency and continuity (Goeman *et al.*, 2016; Care Inspectorate Scotland, 2017; Gräske *et al.*, 2018; Brazil *et al.*, 2018; Local Government Association, 2018; Bosco *et al.*, 2019; Jones *et al.*, 2022; Seetharaman *et al.*, 2022). Multi-agency groups and dementia care networks helped bridge service gaps, while local authorities and ICSs convened collaborative forums to align stakeholders and foster shared accountability (Goeman *et al.*, 2016; Conway *et al.*, 2016; Local Government Association, 2018).

To enable good partnership working in practice, a range of approaches were required. Good partnership working was enabled when organisations committed to shared priorities, pooled resources, and ensured that people living with a dementia and carers were actively involved in shaping services (Gräske *et al.*, 2018; Brazil *et al.*, 2018; Bosco *et al.*, 2019; Seetharaman *et al.*, 2022; Goeman *et al.*, 2016; Jones *et al.*, 2022). Local leadership helped bring statutory, voluntary, and community partners together, while grassroots groups ensured support stayed connected to people's everyday life (Local Government Association, 2018; Aguirre *et al.*, 2023; Healthwatch England, 2024). In practice, success looked like clearer and more joined-up care pathways, quicker access to adaptations and support at home, smoother transitions between services, and people living with a dementia reporting that they felt listened to, included, and supported to live with dignity and independence (Goeman *et al.*, 2016; Doyle *et al.*, 2016; Aguirre *et al.*, 2023; Aworinde *et al.*, 2024; Panagiotidou *et al.*, 2024).

Organisational investment

Organisational investment emerged strongly from the roundtables as a critical enabler of effective leadership and a positive culture in dementia care, though it was less frequently highlighted in the formal literature.

Investing in workforce development strategies ensured that staff were equipped with the skills, knowledge, and confidence to provide person-led care, while also maintaining leadership and cultural priorities at the organisational level. This included providing effective leadership training that enhanced staff management skills, motivated teams, and improved morale (Goh *et al.*, 2022; Handley *et al.*, 2017; Chenoweth *et al.*, 2016).

Workforce stability, capability, and capacity were also essential. For example, promoting staff into leadership roles only when they were prepared, rather than as a response to turnover, allowed leaders to focus on guiding teams rather than firefighting day-to-day staffing issues (Goh *et al.*, 2022; Seetharam *et al.*, 2022; van der Weide *et al.*, 2023).

Together, these organisational investments sustained effective leadership, reinforced a positive learning culture, and created the conditions for staff to deliver consistently high-quality dementia care.

Evidence gaps

Most of the good practice identified had only been assessed in the short term or under idealised conditions, leaving limited understanding of how leadership practices or cultural change are sustained over time.

Roundtable participants also felt it was difficult for regulators to capture the subtle, long-term nature of cultural change.

“Culture is such a tough nut to crack, and I think some of the tools we have as regulators are very blunt instruments, we are serving notices and there’s quite short time frames within those, you’re never going to turn a whole culture in a 3-month period.”

Health and social care regulator, Roundtable 2

Roundtable participants suggested that more discussion and sharing of learning across regulators would be valuable in supporting development of a useful approach for regulators to assess good culture and culture change.

7 Conclusions and considerations

CQC's dementia strategy (see 1-page outline in Appendix 1) sets out an ambition to co-produce evidence based statutory guidance for what good dementia care looks like. This will be applied across CQC's regulatory activity to ensure that their regulatory powers are used to improve the care, support and experience of people living with a dementia and their carers. This review has highlighted good practice across four key areas of the proposed dementia strategy.

Table 1 below shows the key features of good practice and key enablers for this to be implemented, as well as the key learning and considerations for CQC. As well as our four main themes, findings related specifically to family and carers has been pulled out separately, as this was a key area of interest for CQC.

Table 1 Key features of good practice

	Key features of good practice	Key enablers of good practice	Learning and considerations for CQC
Person-led care	• Co-developing dynamic care plans, as ‘living documents • Advance Care Planning, not limited to medical decisions • Promoting meaningful social connections • Involving people in day-to-day activities • Providing health and care in familiar, home-like environments	• Staff trained in communication, including non-verbal approaches • Effective case management or a consistent point of contact • Time and stable staffing to adapt care to the individual • Regular review and updating of care plans	• Observe practice, not just written records • Check that care plans are current and reflect preferences • Look for ACP and case-conference use
Equalities and human rights	• Online tools such as videoconferences can expand access to care for those living with a dementia in remote areas (both providers and those supported) • Videos and websites can make information about dementia more easily accessible • When those living with a dementia feel respected and acknowledged culturally, they are more likely to connect and engage in health and care support • Culturally relevant food and activities have an important role in engagement • Balancing privacy of those supported with provisions for safety.	• Staff confidence needs to be built up when introducing and using digital technologies or other interventions • Considering the digital skills of both staff and those supported • Training can foster culturally competent care, including workshops about the needs and experiences of different groups • Representation in the dementia care workforce can promote cultural sensitivity in dementia care. Recruitment should facilitate diversity and inclusion	• Encourage care providers to ensure information is available online • Highlight good practices in culturally relevant and accessible community services such as memory cafes in key locations • Encourage adoption, where feasible, of technologies that can protect privacy while ensuring safety. • Advocate for equity, diversity and inclusion in

	• Technology such as radar (rather than in-person checks or cameras) can enhance privacy		dementia training and in recruitment of staff
Staffing and training	• Staff would benefit from consistent training on dementia-relevant skills and knowledge • Dementia competency important for all staff, including those working in the care setting in non-caring roles (e.g., catering, management). • Training should cover both general experiences of dementia and techniques for addressing the individual's experiences and needs • Training should emphasise treating each person as an individual and avoiding assumptions • Training should include practical guidance on communication, supporting those experiencing distress and emotions, and recognising body language to address unmet needs	• Care settings need adequate staffing levels and manageable workloads to allow participation in, and implementation of, training • Short, accessible training sessions (e.g., 5-to-10-minute videos or podcasts) can accommodate frequently busy schedules and improve uptake • Train-the-trainer models enhance comprehension of information and staff confidence. They are also useful for scaling up interventions, as only a few staff members at an institution need to receive more time-intensive training • Managers should foster an environment of learning and flexibility to support implementation of training	• Advocate for developing, implementing and/or consolidating standardised dementia training frameworks, to ensure consistency across care settings • Recommend training programmes that focus on practical skills such as communication • Encourage evaluations of long-term training impacts, where appropriate and feasible
Leadership and culture	• There is value in using structured frameworks and audit tools to standardise care and demonstrate effectiveness • Embedding structured quality assurance tools (e.g., TRaCAd) into everyday practice could raise standards	• Supportive, well-trained leaders enable a culture where dignity, respect, and inclusion guide care • Leadership development programmes ensure managers have the skills to inspire, not just clinical expertise	• Assessment approach balances safety, with the ability of staff and leaders to take positive risks • Assessment approach recognises and

	• It is important to conduct regular performance reviews, training evaluations, and team assessments • Risk-averse practices should be replaced, with balanced positive risk-taking • Health and care staff should be empowered to deliver person-led care • Multi-agency collaboration is key to reducing care fragmentation • Embed dementia care into everyday community life through grassroots engagement. For example, mobilising informal networks, advocacy groups, and local organisations • Use collaborative forums where people living with a dementia, carers, providers, and communities shape priorities	• Leaders who model clear, respectful, and empowering communication set standards for daily interactions • Cross-sector collaboration enables consistent, coordinated support across health, social care, and community services • Investment in organisational environments that facilitate and encourage genuine person-led care.	encourages the need for flexibility
Family and carers	• Include family and carers in service design and delivery • There is value in collaboration through care team huddles, case conferences, and family councils • Use collaborative forums where people living with a dementia, carers, providers, and communities shape priorities. • Use real-time, anonymous digital platforms for those being supported, families, and staff to provide feedback	• Arrangements for family overnight stays in care homes can be valuable in supporting inclusion • Advocacy and carer support services are important • There should be easy to use mechanisms in place for family/carers to have ongoing collaboration with staff	• Check whether families are treated as partners, not bystanders • Look for evidence of carers’ voices in planning and decision-making • Encourage co-production between providers and families • Assess how feedback is acted upon in practice

Overall considerations of the findings for CQC

It is positive that CQC are leading by example through their dementia strategy; using their voice in the sector to support and encourage improvements in the care delivered to those living with a dementia and their carers.

CQC should also continue their active collaboration with other external dementia work, for example that led by the Department for Health and Social Care and NHS England. This will ensure learning is shared and there is a collective responsibility, no duplication of efforts, and a clarity of message for providers about ongoing work to support improvements. Ongoing communication and learning (e.g. potentially via a community of practice) should also continue with other UK health and social care regulators to coordinate and articulate a shared vision and strategy for achieving good outcomes for people living with a dementia through robust regulation.

A common theme across the roundtables was the desire for CQC to take a leading role in sharing good practice with providers and commissioners, as well as the general public. Providing evidence-based information on what good practice looks like will help support the wellbeing of people living with a dementia and their carers, by helping the sector to provide consistent, high quality, compassionate care. CQC should continue using existing internal and external communication channels (e.g., blogs, news articles, annual State of Care report etc.) to share examples of innovative dementia care and support engagement with emerging trends and developments. These could be structured thematically to support engagement and be visual and easy to digest (acknowledging existing time pressures on staff).

Once there is a clearer view on CQC's future assessment approach (internal work is ongoing following an external review in 2024), it will be important for good practice guidance on dementia to be mapped to the registration and inspection framework and kept updated as new good practice emerges. Participants in the roundtables were clear that CQC should take a nuanced approach to what good practice looks like, acknowledging that this can differ depending on setting, and type/severity of dementia. CQC's assessment framework should set clear expectations for delivering good support for those living with a dementia and their carers and enable CQC to make sound judgements about quality, safety, and care that services provide. It will also enable those with a dementia and their carers to have a clear view of the support they should be receiving, and how they should be best supported to have better experiences and outcomes. The published inspection/assessment reports across providers and systems (local authorities and ICSs) should also clearly and consistently highlight both good and poor practice in dementia care and support.

There is a current evidence gap around good practice specifically for those from racially minoritised communities, LGBTQ+ individuals, rural populations, and those with young-onset or rare dementias. To build on this, it will be important to engage directly with those with lived experience and sector organisations to continue to capture examples of good practice. CQC’s approach to assessment should also specifically reference support in place around equalities and human rights of those living with and supporting someone with a dementia. This will help achieve CQC’s vision of people experiencing fewer inequalities because of their protected characteristics or dementia diagnosis.

Bibliography

Aguirre, A. *et al*. (2023) 'Designing an interprofessional dementia specialty clinic: Conceptualization and evaluation of a patient-centred model', *Journal of Interprofessional Care*, 37(2), pp. 254–261. doi: 10.1080/13561820.2022.2060194.

Aikman, A. (2023) *Environments for Ageing and Dementia Design Assessment Tool (EADDAT) launches*, Dementia Services Development Centre, University of Stirling, 20 September. Available at: https://www.dementia.stir.ac.uk/newsblog/tax-8y9m9-4pdt5-xfdmp-2ze6s

Alzheimer's Society (2024) 'How many people have dementia in the UK?' Available at: https://www.alzheimers.org.uk/blog/how-many-people-have-dementia-uk (Accessed 1 September 2025)

Alzheimer's Society (2025), 'How much does dementia care cost?' Available at: https://www.alzheimers.org.uk/blog/how-much-does-dementia-care-cost (Accessed 1 September 2025)

Aworinde, J. *et al.* (2024). Co-design of the EMBED-Care Framework as an intervention to enhance shared decision-making for people affected by dementia and practitioners. *Health Expectations*, *27*(1), e13987. https://doi.org/10.1111/hex.13987

Backhouse, A. *et al*. (2017) 'The effectiveness of community-based coordinating interventions in dementia care: a meta-analysis and subgroup analysis of intervention components', *BMC Health Services Research*, 17(1), 717. doi: 10.1186/s12913-017-2677-2.

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 living with dementia living in nursing homes: A cluster-randomised controlled trial'*, PLoS Med*, 15(2), e1002500. doi: 10.1371/journal.pmed.1002500.

Behrman, S., Wilkinson, P. and Lloyd, H. (2017) 'Patient safety in community dementia services: What can we learn from the experiences of caregivers and healthcare professionals?', *Age Ageing*, 46(3), pp. 518–521. doi: 10.1093/ageing/afw220.

Bosco, A., Schneider, J. and Coleston-Shields, D.M. (2019) 'Dementia care model: Promoting personhood through co-production', *Archives of Gerontology and Geriatrics*, 81, pp. 59–73. doi: 10.1016/j.archger.2018.11.003.

Brazil, K. *et al*. (2018) 'Effectiveness of advance care planning with family carers in dementia nursing homes: A paired cluster randomized controlled trial', *Palliative Medicine*, 32(3), pp. 603–612. doi: 10.1177/0269216317722413.

Burke, C. and Charlesworth, P. (2018) *Need2Know Hidden in Plain Sight – Dementia and Learning Disability*. Foundation for People with Learning Disabilities. Available at: ED598963.pdf (Accessed 18 September 2025).

Care Inspectorate Scotland (2017) *My life, my care home*. Available at: my-life-my-care-home.pdf (Accessed: 28 August 2025).

Care Quality Commission (2025a) *Regulations for service providers and managers. Health and Social Care Act 2008 (Regulated Activities): Regulation 18: Staffing*. Available at: https://www.cqc.org.uk/guidance-regulation/providers/regulations-service-providers-and-managers/health-social-care-act/regulation-18 (Accessed 17 September 2025).

Care Quality Commission (2025b) *Brief guide: Mandatory training requirement on learning disability and autism*. Available at: https://www.cqc.org.uk/guidance-providers/nhs-trusts/brief-guides-inspection-teams/mandatory-training-learning-disability-autism (Accessed 17 September 2025).

Care Quality Commission (2023) *Short observational framework for inspection.* Available at: Short observational framework for inspection - Care Quality Commission (Accessed 19 December 2025).

Capstick, A. *et al.* (2021) 'Drawn from life: Cocreating narrative and graphic vignettes of lived experience with people affected by dementia', *Health Expectations*, 24(5), pp. 1890–1900. doi: 10.1111/hex.13332.

Chaudhry, N. *et al.* (2020) 'Montessori intervention for individuals with dementia: Feasibility study of a culturally adapted psychosocial intervention in Pakistan (MIRACLE)'. *BJPsych Open*, 6(4), e69. https://doi.org/10.1192/bjo.2020.49

Chenoweth, L. *et al.* (2015) 'PerCEN trial participant perspectives on the implementation and outcomes of person-centered dementia care and environments', *International Psychogeriatrics*, 27(12), pp. 2045–2057. doi: 10.1017/S1041610215001350.

Chenoweth, L., Stein-Parbury, J. and White, D. (2016) 'Coaching in self-efficacy improves care responses, health and well-being in dementia carers: a pre/post-test/follow-up study', *BMC Health Services Research*, 16, 166. doi: 10.1186/s12913-016-1410-x.

Conway, E.R. and Chenery, H.J. (2016) 'Evaluating the MESSAGE Communication Strategies in Dementia training for use with community-based aged care staff working with people living with dementia: a controlled pretest-post-test study', *Journal of Clinical Nursing*, 25(7–8), pp. 1145–1155. doi: 10.1111/jocn.13134.

Dementia Alliance for Culture and Ethnicity (2016) *The Dementia Alliance for Culture and Ethnicity - Good practice guidance*. Available at: 7351ea_42e057d467a243598f6e1b4cd8d17229.pdf (Accessed: 28 August 2025).

Dementia United (no date). Greater Manchester LGBTQ+ Online Dementia Support Group. Available at: https://dementia-united.org.uk/news/2022/05/05/new-gm-lgbtq-online-dementia-support-group/ (Accessed 02 September 2025).

Department of Health (2013). *Delivering high quality, effective, compassionate care: Developing the right people with the right skills and the right values - A mandate from the Government to Health Education England: April 2013 to March 2015*. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/203332/29257_2900971_Delivering_Accessible.pdf (Accessed 03 September 2025).

D'Cunha, N.M., Isbel, S. and Bail, K. (2023) 'It's like home - A small-scale dementia care home and the use of technology: A qualitative study', *Journal of Advanced Nursing*, 79(10), pp. 3848–3865. doi: 10.1111/jan.15728.

Diaz, L.G. *et al*. (2022) 'Assessment tools for measurement of dementia-friendliness of a community: A scoping review', *Dementia*, 21(5), pp. 1825–1855. doi: 10.1177/14713012221090032.

Doyle, C. *et al.* (2016) 'Videoconferencing and telementoring about dementia care: Evaluation of a pilot model for sharing scarce old age psychiatry resources', *International Psychogeriatrics*, 28(9), pp. 1567–1574. doi: 10.1017/S1041610216000740.

Evans, S.C., Harrison-Dening, K. and Read, K. (2016) ‘Towards the end of life: An in-depth exploration of the role of Admiral Nursing in dementia care (Innovative practice)’, *Dementia*, 17(2), pp. 244–251. doi: 10.1177/1471301216636485.

Fitzpatrick, L. (2018) ‘Practical strategies to help develop dementia-friendly hospital wards’, *Nursing Older People*, 30(2), pp. 30–34. doi: 10.7748/nop.2018.e982.

Goh, A.M.Y. *et al.* (2022) ‘What constitutes “good” home care for people living with dementia? An investigation of the views of home care service recipients and providers’, *BMC Geriatrics*, 22(1), 42. doi: 10.1186/s12877-021-02727-4.

Goeman, D., Renehan, E. and Koch, S. (2016) ‘What is the effectiveness of the support worker role for people living with dementia and their carers? A systematic review’, *BMC Health* Services Research, 16, 285. doi: 10.1186/s12913-016-1531-2.

Gräske, J*. et al*. (2018) ‘Quality of life in persons with dementia using regional dementia care network services in Germany: A one-year follow-up study’, *Health and Quality of Life Outcomes*, 16(1), 181. doi: 10.1186/s12955-018-0990-z.

Griffiths, A.W., Robinson, O.C. and Shoesmith, E. (2021) ‘Staff experiences of implementing Dementia Care Mapping to improve the quality of dementia care in care homes: a qualitative process evaluation’, *BMC Health Services Research*, 21(1), 138. doi: 10.1186/s12913-021-06152-6.

Handley, M., Bunn, F. and Goodman, C. (2017) ‘Dementia-friendly interventions to improve the care of people living with dementia admitted to hospitals: a realist review’, The BMJ, 7(7), e015257. doi: 10.1136/bmjopen-2016-015257.

Ha, N.H.L. *et al.* (2020) ‘Evaluating the Outcomes of a Hospital-to-Community Model of Integrated Care for Dementia’, *Dementia & Geriatric Cognitive Disorders*, 49(6), pp. 598–603. doi: 10.1159/000512290.

Healthwatch England (2024) A local diagnosis: Learning the lessons of Community Diagnostic Centres, Healthwatch Report. Available at: https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/20240828_A%20local%20diagnosis.pdf (Accessed: 28 August 2025).

Heward, M. *et al*. (2021) ‘Impact of “DEALTS2” education intervention on trainer dementia knowledge and confidence to utilise innovative training approaches: A national pre-test – post-test survey’, *Nursing Education Today*, 97, 104694. doi: 10.1016/j.nedt.2020.104694.

Hicks, B. *et al.* (2025). ‘A mapping review of studies exploring the barriers and facilitators to a dementia diagnosis through an intersectionality lens’. *BJPsych Open*, 11(3), e76. https://doi.org/10.1192/bjo.2025.17

James*,* T. *et al.* (2024) ‘Equity in care and support provision for people affected by dementia: experiences of people from UK South Asian and White British backgrounds’. *International Psychogeriatrics*, 36(7), pp. 564-573. https://doi.org/10.1017/S1041610223000121

Janes, M. *et al.* (2025) ‘Understanding the essential components and effectiveness of pre-assessment counselling (PAC) in providing a timely diagnosis according to NHS clinicians’, *Dementia (London, England)*, 14713012251345928. Advance online publication. https://doi.org/10.1177/14713012251345928

Jeffery, S. (2023) *Pilot of a new cognitive assessment tool for detecting dementia in the migrant Somali population*. Good Clinical Practice Network. Available at: https://ichgcp.net/clinical-trials-registry/NCT05163821 (Accessed 26 August 2025).

Jones, E. *et al.* (2022) 'Integrated care for people living with dementia', *Clinics in Integrated Care*, 11, 100095. https://doi.org/10.1016/j.intcar.2022.100095

Jutlla, K. *et al.* (2024) *Developing a place-based model of support for people living with dementia from ethnic minorities: a participatory research approach*. NIHR Funding and Awards. Available at: https://fundingawards.nihr.ac.uk/award/NIHR205153 (Accessed 26 August 2025).

Kanczula, A. (2025, July 31) *Developing the right dementia support for South Asian communities in Greater Manchester*. Alzheimer's Society. Available at: https://www.alzheimers.org.uk/get-support/publications-and-factsheets/dementia-together/right-dementia-support-south-asian-communities-manchester (Accessed 26 August 2025).

King's Fund (2024) The role of integrated care systems in improving dementia diagnosis. Available at: https://www.kingsfund.org.uk/insight-and-analysis/long-reads/role-integrated-care-systems-improving-dementia-diagnosis (Accessed 02 September 2025).

Kishita, N., Hammond, L. and Dietrich, C.M. (2018) 'Which interventions work for dementia family carers?: An updated systematic review of randomized controlled trials of carer interventions', *International Psychogeriatrics*, 30(11), pp. 1679–1696. doi: 10.1017/S1041610218000947.

Kitwood T (1997) Dementia Reconsidered: The Person Comes First. Open University Press, Buckingham

Leeds Beckett University (no date) What Works? Centre for Dementia Research. Available at: https://www.leedsbeckett.ac.uk/research/centre-for-dementia-research/what-works/

Local Government Association (2018) *Dementia Post Diagnostic Support*. Available at: 22.1 Dementia Support Guide for councils_WEB.pdf (Accessed: 28 August 2025).

Luckett, T. *et al*. (2017) 'A facilitated approach to family case conferencing for people with advanced dementia living in nursing homes: Perceptions of palliative care planning coordinators and other health professionals in the IDEAL study', *International Psychogeriatrics*, 29(10), pp. 1713–1722. doi: 10.1017/S1041610217000977.

Magee, M., McCorkell, G. and Guille, S. (2017) 'Feasibility of the Namaste Care Programme to enhance care for those with advanced dementia', *International Journal of Palliative Nursing*, 23(8), pp. 368–376. doi: 10.12968/ijpn.2017.23.8.368

Middleton, L. E. *et al.* (2023) 'Dementia resources for eating, activity, and meaningful inclusion (DREAM) toolkit codevelopment: process, output, and lessons learned'. *Research Involvement and Engagement*, 9(87), pp. 1-16. https://doi.org/10.1186/s40900-023-00497-4

Mitchell, G. and Agnelli, J. (2015) 'Person-centred care for people living with dementia: Kitwood reconsidered', *Nursing Standard*, 30(7), pp. 46–50. doi: 10.7748/ns.30.7.46.s47.

Moenke, L., Handley, M. and Goodman, C. (2023) 'The Influence of care home managers' leadership on the delivery of person-centred care for people living with dementia: A systematic review', *Journal of Nursing Management*, e9872272. doi: 10.1155/2023/9872272.

Moody, E. *et al.* (2024) 'The experience of hospitalisation for people living with dementia: A qualitative exploration of how context shapes experiences', *International Journal of Older People Nursing,* 19(6), e12651. https://doi.org/10.1111/opn.12651

Murray, M.E., Wong Shee, A. and West, E. (2019) 'Impact of the Dementia Care in Hospitals Program on acute hospital staff satisfaction', *BMC Health Services Research*, 19(1), 680. doi: 10.1186/s12913-019-4489-z.

National Collaborating Centre for Mental Health (NCCMH), NHS England (2017) Implementation guide and resource pack for dementia care. NHS England, Leeds. Available at: https://www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/dementia/nccmh_dementia-care-short-guide.pdf

NHS England (2022) Shared decision-making. NHS England. Available at: https://www.england.nhs.uk/personalisedcare/shared-decision-making/

NICE (2018) 'Dementia: assessment, management and support for people living with dementia and their carers'. Available at: https://www.nice.org.uk/guidance/ng97. (Accessed: 4 September 2025).

NIHR (National Institute for Health and Care Research) (2022) 'Continence, dementia, and care that preserves dignity', NIHR Evidence Collection. Available at: https://evidence.nihr.ac.uk/collection/continence-dementia-and-care-that-preserves-dignity/ (Accessed 02 September 2025).

Opinion Leader and Community Action on Dementia Brent (2015) Living with Dementia in today's community: Brent. Available at: https://www-prod.brent.gov.uk/-/media/files/resident-documents/adult-social-care-documents/living-with-dementia-report.pdf?rev=569cb4753677458294492bdd08cd740c (Accessed 02 September 2025).

Panagiotidou, N. *et al.* (2024) 'Towards establishing quality standards on human rights for services in dementia care'. *International Journal of Older People Nursing*, 19(5), e12643. https://doi.org/10.1111/opn.12643

Parveen, S., Peltier, C., and Oyebode, J. R. (2017) 'Perceptions of dementia and use of services in minority ethnic communities: a scoping exercise'. *Health & Social Care in the Community*, 25(2), pp. 734–742. https://doi.org/10.1111/hsc.12363

Royston, C. *et al*. (2020) 'Optimisation of dementia care in care homes: Dementia care framework (innovative practice)', *Dementia*, 19(4), pp. 1316–1324. doi: 10.1177/1471301217740009.

Robinson, O.C., Surr, C. and Ashley, L. (2025) 'Understanding cancer care for nursing home residents living with dementia: An ethnographic study', *Psycho-Oncology*, 34(6), e70184. https://doi.org/10.1002/pon.70184

Sampson, E.L., Vickerstaff, V. and Lietz, S. (2017) 'Improving the care of people living with dementia in general hospitals: Evaluation of a whole-system train-the-trainer model', *International Psychogeriatrics*, 29(4), pp. 605–614. doi: 10.1017/S1041610216002222.

Saragih, I. D. *et al.* (2025) 'A meta-analysis of person-centered care interventions for improving health outcomes in persons living with dementia'. *Worldviews on Evidence-Based Nursing*, 22(1), e12746. https://doi.org/10.1111/wvn.12746

Seetharaman, K. *et al. (*2022) 'Best practices in dementia care: A review of the grey literature on guidelines for staffing and physical environment in long-term care', *Canadian Journal on Aging*, 41(1), pp. 55–70. doi: 10.1017/S0714980820000392.

Skills for Care (2016). *Dementia and diversity: A guide for leaders and managers*. Available at: https://www.skillsforcare.org.uk/resources/documents/Developing-your-workforce/Care-topics/Dementia/Dementia-and-diversity-a-guide-for-leaders-and-managers.pdf (Accessed 02 September 2025).

Skills for Care (2025) 'A Workforce Strategy for Adult Social Care in England'. Available at: A Workforce Strategy for Adult Social Care in England. (Accessed: 4 September 2025).

Smith, S. J. *et al.* (2019). 'An audit of dementia education and training in UK health and social care: a comparison with national benchmark standards'. *BMC Health Service Research,* 19, 711. https://doi.org/10.1186/s12913-019-4510-6

Smith, S.J. *et al.* (2023) *Review of National Memory Assessment Services (MAS): Identifying good practice examples and opportunities for improvement*, Leeds Beckett University (commissioned by NHS England and Improvement Cymru). Available at: des01567_mas_short_report-and-guidelines_digital.pdf (Accessed: 28 August 2025).

Social Care Institute for Excellence (2022) *Deprivation of Liberty Safeguards (DoLS) at a glance*. Available at: https://www.scie.org.uk/mca/dols/at-a-glance/ (Accessed 28 August 2025).

Stamou, V. *et al.* (2022) 'Helpful post-diagnostic services for young onset dementia: Findings and recommendations from the Angela project', *Health & Social Care in the Community*, 30(1), pp. 142–153. doi: 10.1111/hsc.13383.

Stott, J., Sweeney, J.M. and Koschalka, L. (2017) 'People living with dementia as peer workers, challenges, and benefits: A thematic analysis and nominal groups study', *International Psychogeriatrics*, 29(7), pp. 1185–1192. doi: 10.1017/S1041610216002519.

Surr, C. *et al.* (2018) *Dementia Training Design and Delivery Audit Tool (DeTDAT) v4.0: Auditor's manual*. Leeds Beckett University. Available at: https://www.leedsbeckett.ac.uk/-/media/files/research/dementia/dementia-training-design-and-delivery-audit-tool-manual-v4_0.pdf (Accessed 09 September 2025).

Treadaway, C., Taylor, A. and Fennell, J. (2018) 'Compassionate design for dementia care', *International Journal of Design Creativity and Innovation*, 7(3), pp. 144–157. doi: 10.1080/21650349.2018.1501280.

Toms, G. R. *et al.* (2015) 'A systematic narrative review of support groups for people living with dementia'. *International Psychogeriatrics*, 27(9), pp. 1439-1465. DOI: 10.1017/S1041610215000691

Urashima, S., Greiner, C. and Ryuno, H. (2022) 'Factors affecting the quality of dementia care at acute care hospitals: A cross-sectional study', *Journal of Clinical Nursing*, 31(15–16), pp. 2198–2207. doi: 10.1111/jocn.16036.

van der Weide, H. *et al.* (2023) 'Supporting autonomy for people living with dementia living in nursing homes: A rapid realist review', *International Journal of Nursing Studies*, 137, 104382. doi: 10.1016/j.ijnurstu.2022.104382.

Waller, A., Dilworth, S. and Mansfield, E. (2017) 'Computer and telephone delivered interventions to support caregivers of people living with dementia: a systematic review of research output and quality', *BMC Geriatrics*, 17(1), 265. doi: 10.1186/s12877-017-0654-6.

Weiss, J. *et al.* (2020) 'Critical workforce gaps in dementia education and training'. *Journal of the American Geriatrics Society*, 68(3), pp. 625-629. doi: 10.1111/jgs.16341

Woodbridge, R. *et al.* (2018) ‘Use of the physical environment to support everyday activities for people living with dementia: A systematic review’, *Dementia*, 17(5), pp. 533–572. doi: 10.1177/1471301216648670.

Yan, Z., Traynor, V. and Alanzeh, I. (2022) ‘The impact of Montessori-based programmes on individuals with dementia living in residential aged care: A systematic review’, *Dementia*, 22(6), pp. 1259–1291. doi: 10.1177/14713012231173817.

Young Dementia Network (2022) *Good practice in young onset dementia*. Available at: The-Angela-Project-Good-practice-in-young-onset-dementia_WEB_O8-22.pdf (Accessed: 28 August 2025).

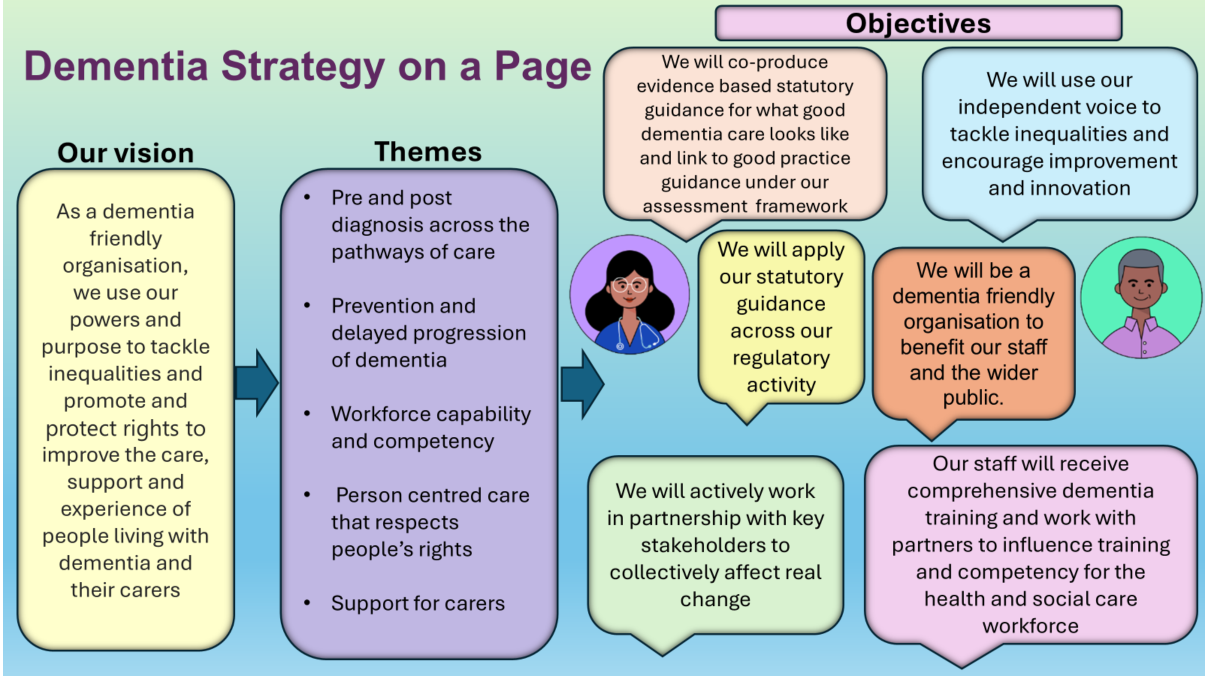
Young, R., Camic, P.M. and Tischler, V. (2016) ‘The impact of community-based arts and health interventions on cognition in people living with dementia: a systematic literature review’, *Aging Mental Health*, 20(4), pp. 337–351. doi: 10.1080/13607863.2015.1011080.

Appendices

Appendix 1: CQC's dementia strategy

This review aligns with CQC's development of a dementia strategy. Work on this so far sets out a clear vision: *as a dementia friendly organisation, CQC will use its powers and purpose to tackle inequalities, protect rights, and improve the care, support and experiences of people living with dementia and their carers*. To deliver on this vision, CQC has identified a number of strategic objectives. These include co-producing evidence-based statutory guidance on what good dementia care looks like and linking this to its wider assessment framework; applying statutory guidance consistently across regulatory activity; and working in partnership with stakeholders to drive collective improvement. The dementia strategy on a page document provided by CQC (alongside partners) can be seen below.

Figure 7.1 CQC's dementia strategy on a page



Dementia Strategy on a Page

Our vision

As a dementia friendly organisation, we use our powers and purpose to tackle inequalities and promote and protect rights to improve the care, support and experience of people living with dementia and their carers

Themes

- Pre and post diagnosis across the pathways of care
- Prevention and delayed progression of dementia
- Workforce capability and competency
- Person centred care that respects people's rights
- Support for carers

Objectives

We will co-produce evidence based statutory guidance for what good dementia care looks like and link to good practice guidance under our assessment framework

We will use our independent voice to tackle inequalities and encourage improvement and innovation

We will apply our statutory guidance across our regulatory activity

We will be a dementia friendly organisation to benefit our staff and the wider public.

We will actively work in partnership with key stakeholders to collectively affect real change

Our staff will receive comprehensive dementia training and work with partners to influence training and competency for the health and social care workforce

CQC's dementia strategy will set out clear expectations for providers and establish a consistent standard of 'what good looks like'. As CQC's assessment approach is currently being reviewed, with consultation taking place in Autumn 2025 and roll-out of the new assessment framework from 2026, the findings from this research will also provide timely insight to support that wider transformation.

Appendix 2: Detailed methodology

The research began with a virtual inception meeting to agree practicalities, clarify scope, and discuss ongoing CQC work on dementia care. Key agreements made at this meeting included:

- Searches would be limited to literature published in the past 10 years (2015-2025). Key research and influential approaches predating this period were also included where relevant to provide historical or theoretical context (for example, Kitwood's work on person-centred care)
- All CQC regulated settings would be included within the search parameters. Within the CQC framework, "sector" refers to: adult social care, primary and community care, hospital / secondary care, specialist care, other (e.g. dentistry).
- The review would focus solely on dementia across all relevant provider settings and stages of care.

Development of search protocol and search process

Stage 1: Gathering documents

Table 2 below outlines the types of literature that was included within the rapid evidence review. Each type of literature is discussed in more detail below.

Table 2 Types of literature

Literature type	Sources
Academic literature	Using databases: Web of Science, Health Systems Evidence, Social Policy and Practice, CINAHL. We also searched the Journal of Dementia Care.
Grey literature	Drawn from search engine searches as well as targeted website searches of key organisations such as other regulators, think tanks, voluntary organisations and Government sources.
Unpublished literature	**Social media:** IFF Research and Centre for Dementia Research (CDR) will utilise LinkedIn to do a call-out for publications. **Existing connections:** We also utilised existing connections to access unpublished literature.

Academic literature

Table 3 shows the search criteria we used for the database searching.

Table 3 Search criteria

Key words	Search strings
Dementia	(Dementia) OR (Alzheimer's) OR (Vascular Dementia) OR (Early-onset) OR (Neurodegenerative) OR (Frontotemporal) OR (Lewy-body) OR (Young onset) OR (Chronic Traumatic Encephalopathy) OR (Creutzfeldt-Jakob) OR (Neurocognitive disorder)
Countries/regions	United Kingdom, England, Northern Ireland, Wales, Scotland, Europe, Japan, Canada, Australia, Netherlands, Austria, New Zealand, Denmark, Norway, and Sweden
Care settings	(Residential) OR (Care setting) OR (Nursing home) OR (Care home) OR (Social care) OR (Supported living) OR (Residential care) OR (Residential home) OR (Nursing Care) OR (Ambulance) OR (Community-based care) OR (Dentist) OR (General Practice) OR (Hospice) OR (Hospital) OR (NHS) OR (Service) OR (Support) OR (Model)
Good practice / quality of care	(Effectiveness) OR (Improvement) OR (Evaluation) OR (Success) OR (Best practice) OR (Person-centred) OR (Person-led) OR (Quality) OR (Safety) OR (Guidance) OR (Safeguarding) OR (Culturally appropriate) OR (Effective) OR (Good practice) OR (Responsive) OR (Barriers) OR (Drivers) OR (Facilitators) OR (Outstanding) OR (Values based practice) OR (Dementia friendly) OR (Evidence-based) OR (Intervention) OR (Innovation) OR (Psychosocial) OR (Training)

Grey literature

Alongside the search of academic databases, we conducted a search of grey literature. We explored the websites of the following organisations:

- Alzheimer's Disease International
- Alzheimer's Research UK
- Alzheimer's Society
- Care Inspectorate (Scotland)

- Care Inspectorate (Wales)
- Department of Health and Social Care (DHSC)
- Healthcare Improvement Scotland
- Healthcare Inspectorate Wales
- King’s Fund
- Local Government Association
- National Institute for Health and Care Excellence (NICE)
- National Institute for Health Research (NIHR)
- NHS England
- Nuffield Trust
- Rare Dementia Support
- Regulation and Quality Improvement Authority (Northern Ireland)
- Skills for Care
- Social Care Institute for Excellence (SCIE)
- UK Dementia Research Institute
- Young Dementia Network
- Age UK
- British Geriatrics Society
- Carers UK
- Dementia UK
- Healthwatch
- National Voices

Unpublished literature

Recognising that much good practice in dementia is unpublished, we adopted the following approaches to gather additional evidence:

- Issued a call-out for unpublished documents via LinkedIn and Twitter/X. A social media post outlining the nature of the research and requesting relevant documents by IFF Research and Professor Sarah Smith.
- IFF Research and Professor Sarah Smith contacted existing networks and professional contacts directly to request further evidence.

We engaged with the following organisations, in addition to any further contacts suggested by the research team:

- Age UK
- British Geriatrics Society
- Carers UK
- Carers Wales
- Carers Scotland
- Carers NI
- Healthwatch Enquiries
- Young Dementia Network

Stage 2: Initial sift

From Stage 1, a total of 2,704 published and unpublished documents were identified. The longlist was then reviewed against the Level 1 inclusion/exclusion criteria set out in Table 4. Duplicate documents were also removed at this stage. Following this initial sift, 468 documents remained and were taken forward to Stage 3 of the review.

Table 4 Level 1 inclusion/exclusion criteria

Inclusion criteria	
Language	English or accredited translations
Countries	Focus on England, Wales, Scotland and Northern Ireland, but secondary interest Europe, Japan, Canada, Australia, Netherlands, Austria, New Zealand, Denmark, Norway, and Sweden
Time period	Focus on the last 10 years (January 2015-April 2025), with some exception for seminal works (e.g. Kitwood). Professor Smith will support with identifying contextual literature outside of the 10-year reference period
Care settings of interest	All settings within CQC's regulatory remit
Dementia types and stages	All types of dementia are in-scope, including Alzheimer's Disease, Frontotemporal Dementia, Lewy Body Dementia, Vascular Dementia All stages of dementia are in-scope, including mild, moderate, advanced The review will also cover from the point of diagnosis to end of life care
Exclusion criteria	
Treatment of dementia	Medication or pharmacological treatment, management intervention or cost
Care settings of interest	Informal dementia care provided by friends and family, outside of a CQC regulated setting

Stage 3: Secondary review of titles and abstracts

468 abstracts and key sections were then reviewed and assessed against the Level 2 inclusion and exclusion criteria set out in Table 5. Abstracts that did not meet any of the Level 2 criteria were excluded, and the remaining abstracts formed the shortlist of relevant literature for subsequent screening and quality assessment.

Table 5 Level 2 inclusion/exclusion criteria

	Inclusion criteria	Exclusion criteria
Relevance to the proposed statutory guidance	Related to one or more of the key topics for the review (i.e. chapters in the draft statutory guidance): • Person-led care • Equalities and human rights • Staffing and training • Leadership and culture	Not related to any of the topics of particular interest
Quality of evidence	The methodology is clear and transparently presented; the methodology reduces bias; assumptions made are clear; conclusions are backed-up by well presented data and findings; limitations and quality have been discussed	Major study limitations; inconsistency of findings; publication bias; no detail on methodology; personal/opinion pieces not based on evidence
Evidence of success	Care setting performance in supporting those living with a dementia (including good practice) and factors contributing to success	Does not have any of the outcomes/impacts/effectiveness of methods associated with the research questions

Quality assessment of full texts

Stage 3 generated a shortlist of 169 documents. Where required, full texts were obtained and screened to identify the final list of the most relevant documents for review. The final selection was based on tighter inclusion criteria, including quality measures adapted from DEFRA guidance. These involved:

- **Scoring the relevance** of the evidence to the research themes on a three-point scale (1 = low, 3 = high), taking into account:
    - The relevance of the method used
    - The relevance of the evidence to the target subject or population
    - The relevance of the intervention assessed
    - The relevance of the outcome measured
- **Scoring the robustness** of the evidence on a three-point scale (1 = low, 3 = high), using defined criteria for each rating.

Scale rating	Description
1	Few or no methodological criteria have been fulfilled. The conclusions of the study are thought likely or very likely to alter (high risk of bias).
2	Some of the methodological criteria appropriate for the study type have been fulfilled and those criteria that have not been fulfilled or not adequately described are thought unlikely to alter the conclusions (risk of bias).
3	All or most of the methodological criteria appropriate for the study type have been fulfilled (low risk of bias).

- **Combine the two scores** from A) and B) into one final measure of quality, i.e., scored from 1 (1*1) up to 9 (3*3) and coded to result in a red-amber-green rating.

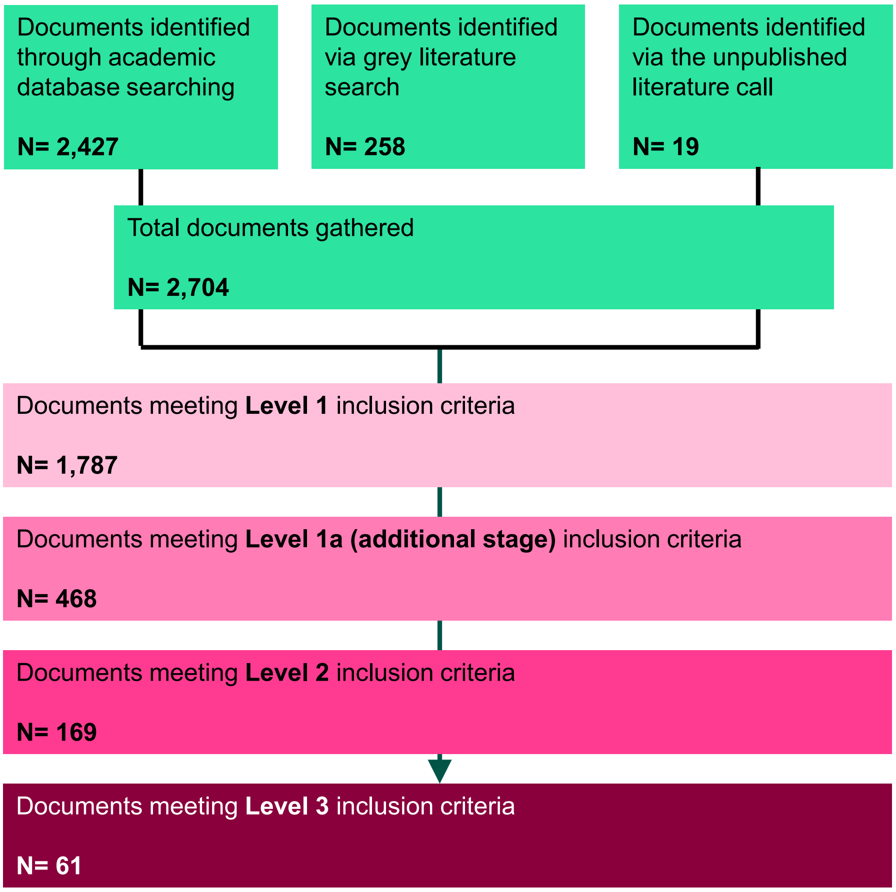
Full review and data extraction

Quality assessment resulted in **61 documents** for a full, detailed review. This was undertaken using a separate analysis framework, carrying forward information collected during the sift and adding narrative content structured around the draft chapters of the dementia statutory guidance: person-led care, equalities and human rights, staffing and training, and leadership and culture.

All 61 documents were reviewed in full and analysed thematically using the four overarching categories of CQC's dementia strategy: person-led care, equalities and human rights, staffing and training, and leadership and culture. Each document was also assessed for how it contributed to the core research questions. Analysis involved collating feedback from each reviewed document, producing summarised insights with page references, recording direct evidence or quotations, and listing article numbers to ensure traceability. Researchers identified recurring patterns and themes, summarised findings in their own words, and applied a strength rating of low, medium, or high to reflect the robustness of the evidence. Key findings of particular relevance to CQC were highlighted and evidence gaps noted. The synthesis phase culminated is a team analysis session, where findings were shared across themes and collectively used to address the research questions.

An outline of the number of documents included at each stage of the sifting process is presented in Figure 2.

Figure 2 Documents at each stage of the sifting process



Stakeholder engagement through roundtables

Three online roundtable events, each lasting two hours, were conducted to enrich the evidence synthesis. The roundtables allowed us to engage with a wider group of experts to contribute to the review. Insight gathered from the roundtables fed into our final report. They were designed to:

- Deepen our understanding of what good looks like in dementia care, building on the literature review findings (roundtable 1, 2 and 3);
- Provide additional insight into any gaps identified in the literature, and explore why those gaps exist (roundtable 1, 2 and 3);
- Provide an opportunity to reflect on how regulation can support improvements in dementia care and the specific role CQC could play in this (roundtable 2).

Roundtable 1: Dementia care experts: Academics and representatives from key sector organisations. Discussions focussed on gathering input around what good looks like in dementia care and provide additional insight into any gaps identified in the literature. Participants were asked to consider the main enablers and barriers to each theme presented, and to suggest ways for CQC to incorporate the themes into regulatory processes.

Roundtable 1 had 9 participants, consisting of researchers and experts across areas of policy, care improvement, and regulation. The following organisations were represented:

- Alzheimer’s Society
- Association for Dementia Studies, University of Worcester
- Dementia Forward
- DeNPRU-QM (Dementia and Neurodegeneration Policy Unit) at Queen Mary University of London
- Hallmark Care Homes
- Leeds Beckett University
- Midlands and Lancashire Commissioning Support Unit
- NHS England
- Social Care Institute for Excellence (SCIE)

Roundtable 2: Other regulators and system partners: Drew on the experiences of other regulators and system partners to identify what’s working, where the challenges lie, and how oversight can evolve to better support person-led, high-quality dementia care across the sector. Participants were asked for any good practices they had seen. They also considered barriers and enablers and how regulation could support good practice.

Roundtable 2 had 8 participants. The following organisations were represented:

- Care Inspectorate Scotland
- Local Government Association
- National Institute for Health and Care Research
- Regulation and Quality Improvement Authority (Northern Ireland)
- Skills for Care

Roundtable 3: Those with lived experience of dementia or supporting someone with dementia: This session focussed on what good looks like in person-led dementia care, and how participants would judge this if they were in the position of a CQC inspector. The lived experience roundtable consisted of three individuals living with a dementia, and five individuals who have or had cared for loved ones with dementia (4 parents, 1 non-specified).

“

IFF Research illuminates the world for organisations businesses and individuals helping them to make better-informed decisions.”

Our Values:

1. Being human first:

Whether employer or employee, client or collaborator, we are all humans first and foremost. Recognising this essential humanity is central to how we conduct our business, and how we lead our lives. We respect and accommodate each individual’s way of thinking, working and communicating, mindful of the fact that each has their own story and means of telling it.

2. Impartiality and independence:

IFF is a research-led organisation which believes in letting the evidence do the talking. We don’t undertake projects with a preconception of what “the answer” is, and we don’t hide from the truths that research reveals. We are independent, in the research we conduct, of political flavour or dogma. We are open-minded, imaginative and intellectually rigorous.

3. Making a difference:

At IFF, we want to make a difference to the clients we work with, and we work with clients who share our ambition for positive change. We expect all IFF staff to take personal responsibility for everything they do at work, which should always be the best they can deliver.

IFF Research

5th Floor
The Harlequin Building
65 Southwark Street
London
SE1 0HR
Tel: +44(0)20 7250 3035
Website: iffresearch.com