Elizabeth's Wish

Better Dementia Care, Safer Hospitals

A national policy initiative designed to deliver safe, accountable, and dignified dementia care across all NHS hospitals, ensuring every patient and family receives the compassion and protection they deserve

To Elizabeth, and to every person living with dementia whose voice too often goes unheard. To the families who face uncertainty, fear, and heartbreak, navigating a system not yet designed for their needs. May this work inspire change, drive accountability, and ensure that dignity, safety, and compassionate care are never optional, but a standard for all.

Statement of Purpose

"To ensure every person living with dementia receives compassionate, lawful, dignified care, free from neglect, discrimination, and avoidable harm, through stronger accountability, better training, and a culture that recognises their humanity above all else."

Elizabeth's Wish exists to drive meaningful, lasting change in how care providers understand, support, and protect people living with dementia. We aim to transform policy and practice so that every interaction, whether medical, personal, or emotional, is guided by empathy, respect, and the fundamental belief that vulnerability should never diminish a person's worth.

Our mission is to amplify the voices of those who cannot always speak for themselves and to ensure that no dementia patient is ever left unseen, unheard, or unsafe.

The purpose of Elizabeth's Wish is to turn personal loss into collective protection. Through this document, we seek to identify the systemic weaknesses that leave dementia patients at risk and to propose practical, achievable reforms that strengthen safety, accountability, and compassion across all care settings.

This work is built on four core commitments:

1. **To Advocate for Those Without a Voice**
   Ensuring that people with dementia are never dismissed, ignored, or labelled as "difficult" when they are simply expressing unmet needs.

2. **To Strengthen Accountability in Care**
   Establishing clearer consequences for neglect, discriminatory behaviour, poor documentation, and breaches of legal duties including the Mental Capacity Act, Safeguarding responsibilities, and professional standards of conduct.

3. **To Improve Training and Awareness**
   Ensuring that every member of staff involved in caring for people with dementia receives high-quality, meaningful training targeted especially around communication, capacity, safeguarding, nutrition, and person-centred support.

4. **To Protect Dignity, Autonomy, and Human Rights**
   Embedding a culture where dementia is understood, where legal rights are upheld, and where compassion is not optional but expected.

In honour of Elizabeth and all those who have suffered from avoidable failures in care, this document seeks to shape a future where dementia patients are recognised not by their condition, but by their humanity and where dignity is guaranteed, not hoped for.

Section 1 - Introduction

Elizabeth Ann Weedon. My grandmother, a wife, a mother, and a woman whose life was built on kindness, entered care needing understanding, dignity, and compassion. Instead, she encountered a system that failed to protect her at her most vulnerable.

She went into care as a person living with dementia who required patience, reassurance, and support. Yet the most basic elements of care; help with eating, drinking, personal hygiene, repositioning, and communication, were often withheld or overlooked. She was left uncomfortable, afraid, and in pain. Preventable pressure sores developed and worsened. Her needs were dismissed as behaviours, not symptoms. Decisions were made without her involvement, and without the legal safeguards she was entitled to.

Her decline was not inevitable. It was shaped, in part, by omissions in care, by a lack of understanding of dementia, and by a culture that too often forgets the humanity of those who cannot advocate for themselves.

As a family, we watched the consequences unfold in real time. We saw how gaps in training, awareness, communication, and accountability can cause genuine harm. We saw how easily a person with dementia can become invisible within a busy care environment, treated as a task rather than a human being.

“Elizabeth’s Wish” was born from that experience. It is not simply a document; it is a call for change.

A call to ensure that no one living with dementia is left neglected because they cannot articulate their needs.

A call to ensure that safeguarding is not optional, but instinctive.

A call to ensure that training is not a tick-box exercise, but a foundation of compassionate practice.

A call to ensure that accountability is clear, fair, and centred on protecting those who cannot protect themselves.

A call to ensure that dignity is not negotiable.

Elizabeth deserved better. Every person living with dementia deserves better.

This document is created in her name, inspired by her experience, and driven by the belief that meaningful, lasting change is both possible and urgently needed.

Her wish was simple: to be safe, respected, and cared for with kindness. Our responsibility now is to turn that wish into a reality for all who follow.

1.1 Context and urgency

Dementia is a growing public-health and health-service challenge in the UK. According to recent estimates, there are approximately 982,000 people living with dementia in the UK as of 2024. [1] In England alone, by December 2024, around 483,000 people had a formal dementia diagnosis — a record high. [2] These trends indicate that substantially more people with dementia will require care in NHS hospitals each year, increasing both clinical demand and the risk of harm if care systems are not dementia-competent. [3, 4]

1.2 Why hospitals matter

Hospitals are frequently unavoidable points of care for people living with dementia — for acute illness, surgery, falls, delirium, and diagnostic workups. The hospital environment and routines (unfamiliar surroundings, nighttime noise, rapid staff turnover, task-focused care) can worsen confusion, precipitate delirium, and increase the risk of adverse outcomes such as falls, poor nutrition and hydration, medication-related harm, and longer lengths of stay [5, 6, 7]. National guidance from the National Institute for Health and Care Excellence (NICE) and other expert bodies emphasise that hospital settings must adapt to the specific needs of people with dementia to prevent avoidable deterioration [8, 9].

1.3 Current gaps and harms

Although guidance exists (NICE guidelines, NHS programmes, and regional Trust strategies), evidence from regulators and independent analysis shows inconsistent implementation across hospitals. The Care Quality Commission's recent *State of Care* reporting and thematic work has identified dementia care as an area of concern, highlighting variability in access, quality, and experience for people with dementia in health and social care settings [10, 11].

The CQC notes record numbers of diagnoses but persistent gaps in service quality and consistency [11]. Independent health policy analysis and sector reporting show many Trusts lack comprehensive, trust-wide training compliance, and that non-clinical staff (porters, domestic staff, reception) often have minimal awareness training despite frequent contact with patients [12, 13].

These shortfalls contribute to avoidable patient harm, family distress, inefficient use of hospital beds, and reputational and financial costs to Trusts [12, 13, 14].

1.4 Evidence that training and accountability work

There is robust evidence that targeted staff training, combined with system-level changes (environmental adaptations, carer involvement, board-level leadership, monitoring and audit), improves process measures and outcomes: better detection and management of delirium, reduced restraint and chemical sedation, more appropriate discharge planning, and improved carer experience and safety outcomes [15, 16, 17].

National programmes and exemplar Trusts that have invested in structured dementia training and governance report measurable improvements [16, 18]. NICE guidance explicitly recommends staff training and organisational systems to support person-centred dementia care [19].

1.5 Rationale for Elizabeth's Wish

"Elizabeth's Wish" converts existing guidance into a consistent, enforceable national framework focused on four aims:

1. Competence: Ensure all hospital staff have role-appropriate dementia skills (universal awareness through to specialist leadership).
2. Accountability: Make dementia care an auditable board-level priority with named leads and clear KPIs.
3. Transparency: Public reporting of training metrics and dementia care outcomes to create incentives for improvement and provide families with information.
4. Partnership: Make carers and families formal partners in care planning and escalation.

This approach closes the gap between guidance and implementation: rather than rely solely on guidance and goodwill, Elizabeth's Wish proposes measurable standards, timelines, and escalation routes linked to existing regulatory levers (CQC, NHS contracts, ICB performance frameworks). The policy is designed to be feasible to implement (phased rollout, central training resources, regional support hubs) and to align with current national commitments described by NHS England and agencies working on dementia pathways.

1.6 Intended audience and use

This introduction and the wider Elizabeth's Wish policy are written for:

- Department of Health and Social Care and the Secretary of State;
- NHS England and Integrated Care Boards (ICBs);
- Trust Boards and Chief Executives;
- Care Quality Commission inspectors and policy teams;
- MPs, patient-advocacy groups and dementia charities;
- Clinical leads and dementia specialists who will operationalise change.

The document supports policy adoption, commissioning changes (NHS Standard Contract), CQC inspection criteria updates, and local Trust implementation plans.

1.7 References

1. Alzheimer's Society — The costs of dementia diagnosis and care in the UK (2024), estimating 982,000 people living with dementia.
   https://www.alzheimers.org.uk/what-we-do/policy-and-influencing/dementia-scale-impact-numbers Alzheimer's Society

2. GOV.UK / NHS England — Dementia Profile: Prevalence and Supporting Well Topics Statistical Commentary, December 2024 update, showing 483,000 people in England with a formal dementia diagnosis.
   https://www.gov.uk/government/statistics/dementia-profile-march-2025-update/dementia-profile-prevalence-and-supporting-well-topics-statistical-commentary-march-2025 GOV.UK

3. Alzheimer's Research UK — Cost of dementia for hospitals in England doubles (2019).
   https://www.alzheimersresearchuk.org/news/cost-of-dementia-hospitals-england-doubles/ Alzheimer's Society+1

4. Alzheimer's Society / Carnall Farrar — The economic impact of dementia in the UK (2024), showing rising healthcare burden and projections of increased incidence.
   https://www.alzheimers.org.uk/what-we-do/policy-and-influencing/economic-impact-of-dementia

5. Designing dementia-friendly hospital environments. PMC — evidence on how unfamiliar hospital environments can cause agitation, disorientation and distress for people with dementia.
   https://pmc.ncbi.nlm.nih.gov/articles/PMC6465876/

6. Hospital care for people living with dementia. NICE / NHS England — notes that admission can trigger distress, confusion or delirium, longer stays, and reduced likelihood of return to independent living.
   https://www.nice.org.uk/about/what-we-do/into-practice/measuring-the-use-of-nice-guidance/impact-of-our-guidance/niceimpact-dementia/ch3-hospital-care

7. How to support a person with dementia during a hospital stay. Alzheimer's Society — describes how hospital admission often leads to increased confusion, agitation, poor eating or drinking, dehydration and behavioural distress.
   https://www.alzheimers.org.uk/get-support/help-dementia-care/during-hospital-stay

8. National Institute for Health and Care Excellence (NICE) Guideline — 'Dementia: assessment, management and support for people living with dementia' (NG97) — warns of increased risks (delirium, disorientation, longer stays, harm) when people with dementia are admitted to hospital and urges careful assessment of admission and environment.
   https://www.nice.org.uk/guidance/ng97/chapter/Recommendations

9. British Geriatrics Society — Position Statement on person-centred acute hospital care for people with dementia, recommending environment and care adaptations, involvement of carers, and individualised care to reduce risk. https://www.bgs.org.uk/resources/bgs-position-statement-person-centred-acute-hospital-care-for-people-with-dementia

10. Care Quality Commission (CQC). State of Care 2023/24: Thematic Review of Dementia Care in Health and Social Care Services. https://www.cqc.org.uk/publications/themed-reports/state-of-care-dementia

11. Care Quality Commission (CQC). Dementia: Monitoring Quality and Safety. https://www.cqc.org.uk/guidance-providers/adult-social-care/dementia

12. Alzheimer's Society. Dementia-friendly hospitals: staff training and awareness. https://www.alzheimers.org.uk/get-support/dementia-care-hospitals

13. The King's Fund. Dementia care in acute hospitals: policy and practice review. https://www.kingsfund.org.uk/publications/dementia-acute-hospitals

14. Health Foundation. Avoidable harms and inefficiencies in hospital dementia care. https://www.health.org.uk/publications/reports/dementia-hospital-care

15. Sampson EL, Blanchard MR, Jones L, et al. Dementia in the acute hospital: prospective cohort study of prevalence and mortality. BMJ. 2009;338:b1012 https://www.bmj.com/content/338/bmj.b1012 (bmj.com)

16. Royal College of Psychiatrists. National Audit of Dementia Care in General Hospitals. https://www.rcpsych.ac.uk/improving-care/national-audits/dementia

17. Alzheimer's Society. Dementia-friendly hospitals: training, environment and governance. https://www.alzheimers.org.uk/get-support/dementia-care-hospitals

18. NHS England. Dementia CQUIN guidance and best practice examples. https://www.england.nhs.uk/long-read/dementia-cquin/

19. National Institute for Health and Care Excellence (NICE). Dementia: assessment, management and support for people living with dementia (NG97). https://www.nice.org.uk/guidance/ng97

Section 2 - Purpose of the Policy

2.1 Overarching Purpose

The purpose of Elizabeth's Wish is to establish a national, enforceable, and measurable system that guarantees safe, skilled, and compassionate dementia care across all NHS hospitals. The policy aims to transform dementia care from a variable, locally interpreted obligation into a standardised national expectation, embedded in governance structures, monitored through evidence-based metrics, and experienced consistently by patients and families.

In short:
to ensure that every person with dementia who enters an NHS hospital receives care that protects their safety, dignity, autonomy, and wellbeing, no matter where they live.

2.2 Why a New Policy Is Needed

Despite existing dementia strategies, training options, and quality standards, there is:

- Inconsistent implementation at Trust level
- Variable training completion across staff groups
- Limited accountability when standards are not met
- Inadequate transparency for families and carers
- Insufficient board-level oversight in many hospitals
- Fragmented regional leadership through ICBs

Elizabeth's Wish addresses these gaps by creating a national, structured, and mandatory framework that supports Trusts and provides accountability where needed.

2.3 The Policy's Key Intentions

To ensure equitable standards across all NHS hospitals

No person with dementia should receive excellent care in one Trust but unsafe, inconsistent care in another.

This policy ensures:

- Uniform minimum standards
- Nationally consistent training
- Mandatory reporting
- Shared frameworks for improvement

To make dementia training universal and mandatory

All staff who interact with people with dementia, clinical and non-clinical, must understand their needs.
This policy establishes:

- Tiered training for all roles
- Annual refresher requirements
- NHS England accreditation pathways
- Monitoring and audit mechanisms

To embed dementia safety into NHS governance

Boards, chief executives, and senior leadership teams must treat dementia care as a core patient-safety priority, not a discretionary initiative.

Elizabeth's Wish creates:

- Board-level Dementia Safety Leads
- Mandatory quarterly reports
- Compliance metrics tied to Trust performance

To empower carers as partners in care

Families and carers often provide essential knowledge and continuity for the person with dementia, yet many feel excluded or unheard in hospital settings.

The policy ensures:

- Formal inclusion in care planning
- Flexible visiting policies
- Carer escalation pathways
- Consistent use of personal profiles ("This Is Me" or equivalent)

To create measurable transparency and accountability

The public and the NHS itself needs clear, easy-to-understand data.

The policy introduces:

- A national dementia care dashboard
- Trust-level performance reporting
- Strengthened CQC inspection criteria
- Improvement notices for Trusts not meeting standards

2.4 Alignment with National Priorities

Elizabeth's Wish supports and strengthens existing system priorities:

NHS England Priorities

- Patient safety
- Workforce development
- Compassionate, person-centred care
- Health inequalities reduction

DHSC Priorities

- Quality improvement
- Supporting informal carers
- Greater transparency in health and care services

ICB Priorities

- Standardised quality across regions
- Better integration between hospital and community dementia pathways

CQC Quality Standards

- Safe care
- Effective care
- Responsive services
- Involvement of people and families
- Workforce competence

Elizabeth's Wish does not introduce a competing agenda, it serves as a structural mechanism that helps the system deliver on goals it already holds.

2.5 Specific, Measurable Policy Objectives

These objectives form the foundation for implementation, evaluation, and accountability.

Objective 1 - Training Compliance

- 95% of staff trained to the appropriate tier within 12 months
- 100% of new staff trained within 6 weeks
- Annual refreshers for all staff
- Board-level reporting each quarter

Objective 2 - Dementia Strategy Implementation

- Trust-level dementia strategies reviewed annually
- Shared national framework for delivery
- Audit of clinical processes (hydration, nutrition, delirium prevention, falls minimisation)

Objective 3 - Carer Partnership Standards

- Carers recognised as partners in care
- Formal involvement in assessments, planning, and discharge
- Written carer inclusion standards adopted by all Trusts

Objective 4 - Governance, Oversight and Reporting

- A named Dementia Safety Lead at each NHS Trust
- Quarterly reporting to ICBs
- National dashboard updated annually
- Mandatory publication of performance outcomes

Objective 5 - Strengthened CQC Regulation

- Dementia care becomes a mandatory inspection domain
- Hospital dementia ratings included in public CQC reports
- Enforcement actions for sustained non-compliance

2.6 What "Success" Looks Like

A successful implementation of Elizabeth's Wish will mean:

For patients:

- Safer, calmer, more dignified experiences
- Fewer falls, less delirium, fewer distress-related incidents
- Care that adapts to their needs

For carers:

- Feeling included, respected, and listened to
- Having clear communication and escalation routes
- Being able to stay closely involved in care
- Not feeling powerless or dismissed

For NHS staff:

- Greater confidence in caring for people with dementia

- Reduced stress and fewer complex incidents
- Clearer guidelines and better leadership support
- More consistent workplace culture

For Trusts:

- Clearer governance
- Improved inspection ratings
- Reduced length of stay and avoidable harm
- Alignment with national quality requirements

For the health system:

- A measurable improvement in dementia care outcomes
- Reduced variation between regions
- Better use of NHS resources
- Stronger alignment between hospital and community dementia pathways

2.7 The Policy's Core Purpose, Summarised

Elizabeth's Wish is designed to:

Create a safer, kinder, more consistent NHS environment for people with dementia by embedding mandatory training, strong governance, carer partnership, and transparent accountability at every level of the hospital system.

Section 3 - Policy Principles

Elizabeth's Wish is underpinned by a clear set of core principles designed to guide all operational decisions, training expectations, governance structures, and cultural change within NHS hospitals. These principles ensure that the policy is not simply a checklist, but a values-driven, person-centred, safety-focused framework that supports sustainable improvement in dementia care.

3.1 Person-Centred Care

Every person with dementia must be recognised as an individual with unique needs, preferences, life history, abilities, and communication styles. Care should be tailored, not standardised.

This principle requires:

- Staff to use personal profiles ("This Is Me" or Trust equivalent) as part of routine care.
- Decisions to be made with the person wherever possible, not for them.
- Adjustments in routine to minimise distress and maintain dignity.
- Recognition of the emotional, sensory, cognitive, and environmental factors influencing behaviour.

3.2 Safety Through Skilled Practice

Safe care for people with dementia depends on competent staff, confident decision-making, early recognition of deterioration, and compassionate communication.

This principle is delivered through:

- Mandatory tiered dementia training for all staff roles.
- Competency checks and annual refreshers.
- Clear pathways for assessing delirium, hydration, pain, falls risk, and sensory needs.
- Accessible clinical guidelines tailored to dementia-specific risks.

Safety is not optional; it is a professional and organisational obligation.

3.3 Equity and Consistency

A person with dementia should receive the same high standard of care in every NHS hospital, regardless of postcode, Trust resources, or local interpretation of guidance.

This principle includes:

- National training requirements.
- Standardised dementia care metrics.
- A unified NHS England framework for compliance.
- External oversight through CQC inspection.
- Transparent reporting to minimise regional variation.

The aim is to eliminate the "lottery of care" currently faced by many families.

3.4 Partnership with Carers

Carers are experts in the lived experience of the person with dementia and must be treated as essential partners, not visitors or observers.

This principle ensures:

- Carers' knowledge informs clinical decisions.

- Carers are involved in assessments, daily routines, and discharge planning.
- Trusts adopt dementia-sensitive visiting policies.
- Hospitals provide clear communication channels and escalation routes for carers.
- Carers are respected as contributors to safety, continuity, and emotional wellbeing.

Carer involvement is not optional, it is fundamental to quality care.

3.5 Dignity, Autonomy, and Human Rights

Hospital processes can inadvertently restrict freedom and dignity for people with dementia. The policy embeds a commitment to uphold the Mental Capacity Act and the rights of every patient.

This principle requires:

- Respect for the person's autonomy and values.
- Least-restrictive decision making.
- Consideration of emotional and psychological impact in care planning.
- Avoidance of practices that contribute to distress, confusion, or loss of dignity.
- Ensuring privacy, choice, and respect at every interaction.

Human rights are central to dementia care, not peripheral.

3.6 Evidence-Based Care

The policy is grounded in national guidance, best practice, and emerging research.

This principle includes:

- Alignment with NICE, CQC, Royal College guidance, and NHS England priorities.
- Use of evidence-based tools for screening, assessment, and escalation.
- Continuous review and updating of training programmes.
- Systematic auditing of key safety indicators.

Evidence must shape practice, not habit or tradition.

3.7 Accountability and Transparency

Trusts must demonstrate compliance, performance, and continuous improvement. Good intentions alone are insufficient.

This principle requires:

- Clear governance structures.
- Board-level oversight.
- Regular reporting to ICBs and NHS England.
- Public transparency through dementia care dashboards.
- Action plans for underperforming Trusts.

Accountability is a driver for improvement, not a mechanism for blame.

3.8 Workforce Support and Culture Change

High-quality dementia care depends on staff who feel supported, respected, and confident—not overwhelmed or unprepared.

This principle ensures:

- Protected time for training.
- Psychological and emotional support for staff.

- Clear escalation pathways and supportive leadership.
- Recognition that dementia care is a professional skill, not “common sense.”
- A positive culture where compassionate care is the norm.

Culture change is essential and must be actively led by senior teams.

3.9 Trauma-Informed and Compassion-Focused Practice

People with dementia often experience fear, confusion, or distress in hospital settings. Trauma-informed care helps prevent escalation, reduce distress, and improve outcomes.

This principle includes:

- Awareness of triggers and predictors of distress.
- Minimising environmental overstimulation.
- Adopting calm, slow, reassuring communication styles.
- Avoiding unnecessary interventions that may cause harm.
- Ensuring staff understand behavioural expressions as communication, not “challenging behaviour.”

Compassion is a clinical intervention, not an optional extra.

3.10 Continuous Learning and Improvement

Dementia care requires ongoing development at individual, team, and system levels.

This principle includes:

- Routine evaluation of training effectiveness.
- Learning from incidents, feedback, and audits.
- Sharing best practice across Trusts and ICBs.
- Annual review of strategies and frameworks.
- Encouraging staff to innovate and improve care.

Improvement is not a one-off project; it is a continuous cycle.

3.11 Sustainability and Integration

The policy ensures improvements are long-term and connected to the wider dementia pathway.

This principle includes:

- Integration with community, primary care, and social care dementia systems.
- Consistent handover processes.
- Training that is adaptable to workforce changes.
- Embedding dementia into strategic planning and workforce development.

Elizabeth’s Wish aims to create lasting change, not a temporary initiative.

Section 4 - Policy and Scope

The scope of Elizabeth's Wish defines the settings, staff groups, patient populations, and organisational structures to which the policy applies. Establishing a clear scope ensures that all elements of the NHS understand their responsibilities and that the policy can be implemented consistently across the country. The scope also clarifies what is included, what is excluded, and how this policy interacts with wider national standards.

4.1 Settings Covered by the Policy

This policy applies to all NHS acute hospital settings in England where people with dementia may receive assessment, treatment, or care. This includes:

- Emergency Departments including Urgent Care Centres and Same Day Emergency Care
- Acute medical and surgical wards
- Frailty assessment units
- Clinical decision units
- Intensive care and high dependency areas
- Outpatient departments
- Day surgery and procedure units
- Ambulatory care
- Radiology and diagnostic departments

Any environment where a person with dementia interacts with NHS hospital services falls within the policy's remit.

Community hospitals, mental health inpatient units, GP practices, and care homes are not the primary targets of this policy; however, the standards within Elizabeth's Wish may be adopted voluntarily by these settings, and integration with community dementia pathways is strongly encouraged.

4.2 Patient Groups Within Scope

The policy applies to any person living with dementia, regardless of:

- Diagnosis type (e.g., Alzheimer's, vascular, Lewy Body, FTD, mixed dementia)
- Stage of dementia
- Formal diagnosis status (recognising that many individuals remain undiagnosed)
- Comorbidities (e.g., delirium, frailty, learning disability, Parkinson's disease)
- Communication abilities
- Age or socioeconomic background

It also applies to people who present with symptoms suggestive of dementia but have not yet been diagnosed. This is critical, as many patients arrive at hospital with cognitive impairment that has not been formally recognised.

4.3 Staff Groups Within Scope

Elizabeth's Wish applies to all NHS hospital staff who may interact with people living with dementia, not solely clinical practitioners. This reflects the understanding that safe dementia care requires a whole-hospital approach.

The policy covers:

Clinical staff:

- Doctors (all grades and specialties)

- Nurses and nursing associates
- Healthcare assistants
- Allied health professionals (OT, physio, SLT, dieticians, radiographers)
- Pharmacists and pharmacy technicians
- Paramedics working in hospital-based services
- Mental health liaison teams
- Frailty teams

Non-clinical staff:

- Porters
- Reception and clerical staff
- Domestic and cleaning staff
- Volunteers
- Catering teams
- Security staff
- Transport and ambulance liaison staff

The policy recognises that every interaction can influence safety, dignity, and wellbeing.

4.4 Organisational Structures Within Scope

Elizabeth's Wish applies to:

- NHS Trusts (acute and specialist)
- Trust Boards and Non-Executive Directors
- Integrated Care Boards (ICBs)
- NHS England regional teams
- CQC inspectors assessing acute services

Responsibilities will be clearly defined later in the document, but scope establishes that this is not solely a ward-level initiative, it is a system-wide policy that must be reflected in governance, workforce planning, training budgets, and strategic priorities.

4.5 Areas Explicitly Included

The policy specifically encompasses:

- Mandatory dementia training for all staff
- Dementia-specific clinical care standards
- Delirium recognition and prevention
- Hydration and nutrition monitoring
- Falls, agitation, and distress minimisation
- Ward environment adaptations
- Carer access and involvement
- Clinical documentation including personal profiles
- Governance, reporting, and oversight frameworks
- Performance monitoring at Trust, ICB, and national levels
- Transparency and publication of standards
- Culture change and leadership responsibilities

This policy is not merely educational, it is structural and operational.

4.6 Areas Explicitly Excluded

To maintain clarity and strategic focus, this policy does not cover:

- The diagnosis or long-term progression management of dementia in the community
- Social care funding or local authority responsibilities

- Mental Health Act processes and inpatient psychiatric care
- Residential care home regulations
- NHS Continuing Healthcare criteria
- Pressure ulcer management in non-dementia-specific contexts
- Any non-NHS provider, unless they voluntarily adopt the standards

These areas may interface with dementia care but fall outside the enforceable scope of Elizabeth's Wish.

4.7 Timeframe and Deliverability Scope

The policy's scope is designed to:

- Be deliverable within existing NHS structures
- Align with current CQC frameworks
- Integrate with national dementia strategies
- Allow staged implementation without the need for legislation
- Support rapid adoption by Trust Boards

Although the policy may eventually inform legislative change, it is intentionally structured to be implementable immediately through NHS England guidance, Board responsibilities, and ICB oversight mechanisms.

4.8 Geographic Scope

Elizabeth's Wish is designed for implementation in England only, as health policy is devolved. However:

- NHS Scotland
- NHS Wales
- Health and Social Care Northern Ireland

may adopt or adapt the policy framework if desired, and the document can be used to support cross-nation discussions on dementia safety.

4.9 Summary of Scope

In summary, Elizabeth's Wish covers:

- All NHS hospitals in England
- All staff groups
- All people living with dementia, diagnosed or suspected
- All hospital interactions across the patient journey
- All levels of NHS oversight and governance

It is not a narrow policy, it is a whole-hospital and whole-system approach to dementia safety

Section 5 - Definitions and Key Terms

This section provides precise definitions of terms used throughout Elizabeth's Wish. Consistent terminology ensures that NHS staff, Trust Boards, regulatory bodies, and policymakers interpret the policy uniformly and apply standards consistently across all settings.

5.1 Dementia

Dementia is defined as a progressive syndrome caused by diseases of the brain, characterised by deterioration in cognitive function beyond what might be expected from normal ageing. This includes impairment in memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Dementia affects emotional control, social behaviour, and motivation.

Dementia encompasses, but is not limited to:

- Alzheimer's disease
- Vascular dementia
- Dementia with Lewy bodies
- Frontotemporal dementia
- Mixed dementia
- Parkinson's disease dementia
- Rare dementias (e.g., Posterior Cortical Atrophy, primary progressive aphasia)

This definition aligns with NICE, NHS England, and WHO standards.

5.2 Undiagnosed or Suspected Dementia

People who present with cognitive impairment, memory loss, disorientation, or behavioural changes without a formal diagnosis are considered within scope. Hospital admission often uncovers previously unrecognised dementia; thus, the policy applies to all individuals for whom dementia is suspected.

5.3 Delirium

Delirium is defined as an acute, fluctuating disturbance of attention, awareness, and cognition, often triggered by illness, infection, dehydration, or medication. Delirium is common in people with dementia and significantly increases the risk of harm.

Elizabeth's Wish recognises delirium assessment and management as a core component of dementia care.

5.4 Carer / Family Carer

A carer (also known as an informal or unpaid carer) is a person who provides regular, ongoing support to someone with dementia. This may include family members, partners, friends, or neighbours.

For the purpose of this policy, a carer is defined by their relationship and role, not by legal documentation. A carer is considered a partner in care, not a visitor.

5.5 Person-Centred Care

Person-centred care refers to an approach that recognises and values the individuality, preferences, history, abilities, and emotional needs of a person with dementia. It requires adapting care to the person—not expecting the person to adapt to the environment.

This definition underpins all principles within Elizabeth's Wish.

5.6 Dementia Training (Tiered Framework)

To ensure clarity, the policy defines three tiers of dementia training:

Tier 1, Dementia Awareness

- Applies to all staff, including non-clinical.
- Covers basic understanding of dementia and communication approaches.

Tier 2, Dementia Skilled Practice

- Applies to all clinical staff and those providing direct care.
- Covers assessment, distress reduction, person-centred interventions, and care planning.

Tier 3, Dementia Leadership

- Applies to senior clinicians, managers, dementia leads, and educators.
- Covers advanced practice, service design, governance, and quality improvement.

These definitions correspond to national frameworks (e.g., Dementia Training Standards Framework).

5.7 Dementia Strategy

A Dementia Strategy is the Trust-level plan outlining how dementia care will be delivered, monitored, improved, and governed. It includes:

- Workforce planning
- Training compliance
- Clinical guidelines
- Environmental improvements
- Carer involvement policies
- Patient safety metrics
- Annual review mechanisms

Elizabeth's Wish requires each Trust to have an up-to-date strategy aligned with national standards.

5.8 Dementia Safety Lead

A Dementia Safety Lead is a senior Trust-level role responsible for:

- Dementia training compliance
- Clinical pathways
- Governance and reporting
- Quality assurance
- Staff support
- Carer involvement standards
- Audit oversight

This role must be at a senior clinical or managerial level and report directly to the Trust Board.

5.9 Reasonable Adjustments

Reasonable adjustments refer to modifications in care, communication, environment, or processes to ensure equitable access and safety for people with dementia. Examples include:

- Quieter waiting areas
- Flexible mealtimes

- Simplified communication
- Intentional rounding
- Modified assessment methods
- Extended time for decision-making

This aligns with the Equality Act 2010.

5.10 Hospital Settings

For this policy, "hospital settings" include any NHS-run location where care, assessment, investigation, or treatment is provided. This includes emergency departments, wards, procedure units, diagnostics, outpatient clinics, and observation areas.

Independent providers are not mandated but may voluntarily adopt the standards.

5.11 CQC Regulation

CQC regulation refers to statutory inspection processes assessing whether NHS Trusts deliver safe, effective, responsive, caring, and well-led services. Within this policy, dementia care becomes an integral part of all five inspection domains.

5.12 Integrated Care Boards (ICBs)

ICBs are statutory NHS organisations responsible for planning and funding local health services. In the context of Elizabeth's Wish, ICBs oversee:

- Monitoring Trust compliance
- Supporting training uptake
- Addressing performance gaps
- Ensuring integration with community dementia pathways

5.13 Behavioural Expression / Distress Response

This term replaces outdated language such as "challenging behaviour." It recognises that expressions such as agitation, fear, shouting, withdrawal, or restlessness are forms of communication reflecting unmet needs, distress, pain, or confusion.

5.14 Carer Passport / Carer ID

A tool allowing carers to access wards, participate in care activities, escalate concerns, and receive support. This is part of the policy's carer partnership framework.

5.15 Core Hospital Journey

This refers to all stages from admission to discharge:

- Arrival / ED
- Assessment
- Inpatient care
- Diagnostics
- Therapy
- Multidisciplinary planning
- Discharge coordination
- Handover to community services

The policy applies to the entire journey.

5.16 Summary of Key Terms

The policy uses consistent terminology across all sections to ensure clarity in:

- Standards
- Responsibilities
- Training
- Governance
- Clinical expectations
- Carer involvement

Section 6 - Rationale and Evidence

6.1 Introduction

The experience outlined in Section 1 illustrates the profound consequences of inadequate dementia care within the acute hospital system. While deeply personal, it is not an isolated event. Across NHS hospitals, people with dementia routinely encounter environments, systems, and care practices that are not designed to meet their needs [2,14].

The purpose of this section is to set out the national rationale for Elizabeth's Wish: why improved dementia care is necessary, urgent, and aligned with NHS strategic objectives, and why current approaches are insufficient.

6.2 Dementia and Hospitalisation: A National Challenge

6.2.1 Prevalence and Demographic Reality

- Dementia currently affects an estimated 900,000 people in the UK, projected to reach 1.6 million by 2040 [1].
- People living with dementia occupy a significant proportion of hospital beds, with NHS England reporting substantial bed-day use and acute care dependency [2,4].
- People with dementia experience longer hospital stays, contributing disproportionately to total bed-days and resource use compared with people without dementia [3,4].
- The NHS is therefore already a major dementia care provider, even though acute hospitals were never designed for this role.

6.2.2 Hospital Admission Is Especially Harmful for People with Dementia

Research consistently shows that people with dementia face:

- A higher risk of falls, requiring targeted hospital improvement programmes [5]
- Increased vulnerability to poor nutrition, dehydration and weight loss [6]
- A significantly heightened risk of delirium during hospitalisation [7]
- Increased mortality associated with acute hospital admission [8]
- Functional decline and loss of independence following hospital stays [9]

Hospitalisation for people with dementia is often traumatic, disorienting, and dangerous, yet avoidable harm remains widespread.

6.3 Systemic Gaps in Dementia Care

6.3.1 Workforce Knowledge and Confidence

National audits repeatedly identify:

- Wide variation in staff dementia-training coverage across NHS Trusts [10,11]
- Low confidence among staff in managing distress or complex behaviours [10]
- Inconsistent ability to distinguish between dementia, delirium, and mental health conditions [11]
- Variable communication skills and approaches with families [12]
- Delays in recognising unmet needs or escalating concerns [13]

Existing training requirements are non-mandatory, inconsistently implemented, and not linked to governance [10,12].

6.3.2 Lack of Accountability and Governance

Although many Trusts have dementia strategies, they often:

- Sit on shelves without implementation plans
- Lack Board-level ownership [14]
- Are not measured against outcomes
- Rely on individual enthusiasm rather than system requirements
- Are excluded from formal regulatory enforcement

Elizabeth's Wish introduces clear governance, reporting, and accountability mechanisms that are currently missing [10,14].

6.3.3 Fragmentation of Care Across the Hospital Journey

People with dementia experience:

- Long waits in Emergency Departments [15]
- Noisy, overstimulating environments
- Separation from carers
- Inconsistent care between wards
- Delayed discharge, particularly for older adults with cognitive impairment [16]
- Poor handover back to community services

The absence of a unified, dementia-aware care pathway leads to distress, deterioration, and avoidable harm [14, 15, 16].

6.4 Carer Experiences: A System Under Strain

Carers, the people who know the individual best, frequently report:

- Being treated as visitors, not partners
- Exclusion from decision-making
- Poor communication
- Challenges in providing personal care
- Lack of updates or involvement
- Distress at witnessing avoidable decline

National surveys highlight that carer involvement remains one of the weakest aspects of hospital dementia care [17].

6.5 Consequences of Inadequate Dementia Care

Clinical Consequences

- Increased delirium incidence [7]
- Higher susceptibility to hospital-acquired conditions, including pressure ulcers and infections [18]
- Increased risk of falls and injuries [5]
- Medication-related problems
- Significant functional decline, impacting recovery and independence [9]

Emotional and Psychological Consequences

- Fear, trauma, confusion, and distress
- Long-term psychological harm to patients and families
- Increased carer burden and burnout [17]

Long-Term Social Consequences

- Increased likelihood of needing long-term care following admission [9]
- Breakdown of independence

- Loss of mobility and confidence
- Greater social isolation

Financial Consequences

Hospitals incur substantial additional costs due to:

- Extended length of stay [4]
- Additional interventions caused by avoidable harm [3,18]
- Higher readmission rates
- Increased staffing pressures

Dementia-related pressures on hospitals cost the NHS an estimated £2.7–3.0 billion annually [3].

6.6 Why Current National Guidance Is Not Enough

Existing national standards (e.g., NICE guidance, Dementia Training Standards Framework) are:

- Not mandatory
- Inconsistently implemented [10,12]
- Poorly audited
- Inadequately funded
- Lacking enforceable mechanisms
- Unevenly prioritised across Trusts [14]

Elizabeth's Wish provides the missing framework for mandatory implementation, monitoring, and accountability.

6.7 The Strategic Alignment Case

This policy strongly aligns with:

- NHS Long Term Plan priorities
- Ageing Well commitments
- Patient Safety Strategy
- The CQC's updated regulatory framework [14]
- NHS workforce development priorities [10,11]
- Carer-involvement duties [17]
- Health inequalities reduction programmes

Improving dementia care is therefore not an "additional task". It is central to the NHS's core mission.

6.8 Summary: Why Change Is Necessary Now

Elizabeth's Wish is urgently needed because:

- Dementia prevalence is rising rapidly [1]
- Hospital care is high-risk for this population [5–9]
- Avoidable harm remains common
- Families experience exclusion and distress [17]
- Staff lack confidence and training [10–12]
- Trusts lack accountability [14]
- National guidance is inconsistently applied [10–12,14]
- There is no national, mandatory, enforceable standard

A policy-driven national framework is the only effective way to ensure safe, compassionate, and dignified care for people with dementia across all NHS hospitals.

6.9 References

1. Alzheimer's Society — The annual costs of dementia (UK) (2024). https://www.alzheimers.org.uk/sites/default/files/2024-05/the-annual-costs-of-dementia.pdf

2. NHS England — RightCare: Dementia scenario / Long read (includes analysis of hospital bed-occupancy and impact). https://www.england.nhs.uk/long-read/rightcare-dementia-scenario/

3. Alzheimer's Research UK — Cost of dementia for hospitals in England doubles (press release & analysis; £2.7bn figure). https://www.alzheimersresearchuk.org/news/cost-of-dementia-hospitals-england-doubles/

4. Alzheimer's Society — Dementia: contribution to health metrics / bed-days & length of stay (economic analysis) (2024). https://www.alzheimers.org.uk/sites/default/files/2024-09/Dementia-contribution-health-metrics.pdf

5. NHS England — A falls improvement programme for people with dementia (case study) / falls risk and guidance. https://www.england.nhs.uk/atlascasestudy/a-falls-improvement-programme-for-people-with-dementia/

6. British Dietetic Association (BDA) — Eating and drinking difficulties in dementia (nutrition, dehydration, malnutrition risks). https://www.bda.uk.com/resource/eating-and-drinking-difficulties-in-dementia.html

7. Inouye S.K. — Delirium in hospitalized older patients: recognition and risk (authoritative review on delirium incidence & outcomes). https://pubmed.ncbi.nlm.nih.gov/9894730/

8. Sampson E.L., et al. — Survival / mortality after unplanned acute hospitalisation for people with dementia (study on increased mortality risk). https://onlinelibrary.wiley.com/doi/full/10.1002/gps.3919

9. Sampson E.L. — Dementia in the acute hospital: prospective cohort study of prevalence and outcomes (functional decline and hospital outcomes). https://pubmed.ncbi.nlm.nih.gov/19567898/

10. Healthcare Quality Improvement Partnership (HQIP) / Royal College of Psychiatrists — National Audit of Dementia (Round 5, National Report, 2023) (findings on training, governance and staff confidence). https://www.hqip.org.uk/wp-content/uploads/2023/08/Ref.-403-National-Audit-of-Dementia-Care-in-General-Hospitals-Round-5-National-Report-FINAL.pdf

11. Smith S.J., Parveen S., et al. — An audit of dementia education and training in UK health and social care: comparison with national benchmark standards (2019), shows variation and gaps in training. https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-019-4510-6

12. National Audit of Dementia / Royal College of Psychiatrists — Communication and staff skills findings (rounds 4–5) (evidence of inconsistent communication practice). https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/national-clinical-audits/national-audit-of-dementia/round-5/nad-r5-accessible-report.pdf

13. NHS England — Dementia programme and preparation for disease-modifying treatments / patient safety and incident data references (insight on missed needs and escalation). https://www.england.nhs.uk/long-read/dementia-programme-and-preparation-for-new-alzheimers-disease-modifying-treatments/

14. Care Quality Commission (CQC) — Cracks in the pathway / State of Care findings on dementia in hospitals (themed review; variability and governance issues). https://www.cqc.org.uk/publications/themed-inspection/cracks-pathway

15. NHS England — Emergency care / A&E statistics & dementia ED outcomes (context on waits and ED experience). https://www.england.nhs.uk/statistics/statistical-work-areas/ae-waiting-times-and-activity/

16. National Audit Office (NAO) — Discharging older patients from hospital (2016), evidence on delayed discharge and bed-day impacts. https://www.nao.org.uk/reports/discharging-older-patients-from-hospital/

17. Carers UK — State of Caring survey reports (2023–2024): carers' experiences and involvement in hospital care & discharge. https://www.carersuk.org/policy-and-research/state-of-caring-survey/

18. NHS Resolution / NHS Improvement — Hospital-acquired pressure ulcers and falls (reports & data on HAPUs / avoidable harms). https://resolution.nhs.uk/wp-content/uploads/2022/03/3-NHS-Resolution-ED-report-Hospital-acquired-pressure-ulcers-and-falls.pdf

Section 7 - Strategic Objectives of Elizabeth's Wish

Elizabeth's Wish establishes a national commitment to ensuring that every person with dementia receives safe, dignified, and person-centred care throughout their hospital journey. The strategic objectives outlined in this section describe the overarching aims that guide the policy's standards, governance requirements, and implementation framework.

These objectives do not prescribe operational detail; instead, they set the vision and intent for what the policy seeks to achieve across all NHS hospitals.

7.1 Improve Safety and Reduce Avoidable Harm

To ensure that people living with dementia receive care that protects them from preventable risks, including distress, delirium, falls, malnutrition, dehydration, and accelerated functional decline. Hospital environments, clinical practices, and staff competencies must consistently support safety for individuals with cognitive impairment.

7.2 Ensure Dignity, Compassion, and Respect Throughout Hospital Care

To guarantee that every person with dementia is treated with humanity, understanding, and respect. This includes supporting their emotional wellbeing, preserving identity, maintaining autonomy where possible, and recognising the person behind the diagnosis.

7.3 Embed Person-Centred Dementia Care as a Core NHS Standard

To integrate person-centred dementia care into everyday hospital practice, ensuring that care plans, communication approaches, and clinical interventions are tailored to the individual's needs, history, preferences, and abilities.

7.4 Strengthen Workforce Skills and Confidence

To equip all hospital staff, clinical and non-clinical, with the knowledge, attitudes, and skills required to care for people with dementia safely and effectively. Dementia competence should be an expected standard, not an optional add-on.

7.5 Establish Clear Accountability and Governance Across the NHS

To ensure that leadership responsibility for dementia care is embedded at Trust Board level, supported by mandatory strategies, transparent reporting, and external oversight. Effective dementia care must be monitored, evaluated, and governed with the same seriousness as other patient safety priorities.

7.6 Improve Carer Involvement and Partnership in Care

To recognise carers as essential partners and ensure they are included in communication, decision-making, and daily support. Carers must be enabled, not obstructed, to contribute to the wellbeing of the person they know best.

7.7 Reduce Inequalities and Variation in Hospital Dementia Care

To deliver consistent, equitable standards across all NHS hospitals regardless of geography, patient complexity, or local resources. No person with dementia should receive lower-quality care because of where they happen to be admitted.

7.8 Enhance Patient Experience and Overall Outcomes

To ensure that people with dementia experience reassurance, comfort, clarity, and continuity during their hospital stay, and that outcomes such as independence, mobility, cognitive stability, and quality of life are prioritised.

7.9 Strengthen Integration Between Hospital and Community Dementia Pathways

To promote seamless transitions between acute care, primary care, community teams, memory services, and social care. Hospital care should reinforce, not disrupt, a person's long-term wellbeing and support network.

7.10 Promote a Culture of Learning, Improvement, and Compassion

To foster a culture where staff feel supported to develop, reflect, learn, and raise concerns; where excellence in dementia care is recognised; and where continuous improvement is embedded across the system.

7.11 Summary

These objectives form the backbone of Elizabeth's Wish. They articulate a national vision for hospital dementia care that is safe, compassionate, skilled, accountable, and centred on the needs and dignity of each individual. All subsequent sections, standards, roles, training, monitoring, and implementation, are designed to deliver these overarching aims.

Section 8 - Mandatory Standards for NHS Hospitals

The following standards represent the minimum requirements that all NHS Trusts must meet under Elizabeth's Wish. These standards ensure that people living with dementia receive safe, dignified, and person-centred care throughout their hospital journey. Compliance with these standards is mandatory and subject to internal and external monitoring.

8.1 Leadership and Governance Standards

8.1.1 Board Accountability

Every NHS Trust must assign clear responsibility for dementia care at board level. This includes:

- A named Executive Lead for Dementia
- Regular reporting to the Board on dementia care quality, safety, and outcomes
- Oversight of training compliance and strategy implementation

Dementia care is to be treated as a core patient safety priority, not a specialist or optional domain.

8.1.2 Trust-Level Dementia Strategy (Mandatory)

Each Trust must maintain a comprehensive Dementia Strategy that:

- Is reviewed and approved by the Trust Board annually
- Sets measurable objectives
- Includes training plans, workforce development, and environmental improvements
- Establishes mechanisms for audit, evaluation, and continuous improvement

The strategy must be publicly accessible.

8.1.3 Dementia Safety Lead

A senior Dementia Safety Lead must be appointed to oversee:

- Clinical pathways
- Standards implementation
- Training delivery and compliance
- Carer involvement structures
- Audit and data reporting
- Staff support and escalation routes

This role must have authority across the organisation.

8.2 Workforce Standards

8.2.1 Mandatory Dementia Training

All staff working in hospital settings must complete dementia training appropriate to their role, in alignment with the national Dementia Training Standards Framework.

Requirements:

- Tier 1 training for all staff (clinical, non-clinical, administrative, security, estates, volunteers)
- Tier 2 training for staff providing direct care
- Tier 3 training for senior clinicians, managers, leaders, and educators

Training compliance must be:

- Monitored monthly
- Reported quarterly to the Trust Board
- Submitted annually to the ICB and CQC

8.2.2 Staff Competence and Confidence

Trusts must demonstrate that staff have the skills and confidence to:

- Communicate effectively with people with dementia
- Recognise distress and unmet needs
- Differentiate dementia from delirium
- Deliver person-centred care
- Involve carers appropriately
- Escalate concerns relating to safety or wellbeing

Assessment of competence must be included in appraisal and supervision processes.

8.3 Care Standards

8.3.1 Person-Centred Care Planning

All people with dementia must have a personalised care plan that includes:

- Communication needs
- Personal preferences and routines
- Risks, anxieties, and triggers
- Mobility and independence goals
- Hydration and nutritional needs
- Pain management requirements
- Involvement of carers

Plans must be accessible to all staff involved in the person's care.

8.3.2 Identification and Flagging

Hospitals must have systems to clearly identify:

- Confirmed dementia diagnoses
- Suspected dementia
- Delirium risk
- Communication or behavioural needs
- Carer involvement requirements

This information must be visible across clinical systems and handovers.

8.3.3 Delirium Prevention and Management

Hospitals must implement structured approaches for:

- Early detection of delirium
- Proactive delirium prevention strategies
- Evidence-based management
- Family involvement
- Routine delirium screening within 6 hours of admission

Delirium is to be recognised as a major safety risk.

8.3.4 Safe Hospital Environments

Trusts must ensure that environments are supportive for people with dementia, including:

- Clear visual cues and signage
- Reduction of avoidable noise and overstimulation
- Access to safe walking spaces
- Dementia-friendly toilet and bathroom design
- Protected mealtimes
- Appropriate lighting and layout

Environmental changes must be included in annual capital or estates planning.

8.4 Carer Partnership Standards

8.4.1 Carers as Partners in Care

Carers must be recognised as essential partners, not visitors.
Trusts must ensure:

- Flexible access policies
- Involvement in care planning
- Participation in daily routines where appropriate
- Clear communication during admission, treatment, and discharge
- Access to support and escalation routes

8.4.2 Carer Identification Systems

Each Trust must use a Carer Passport or Carer ID to:

- Confirm the carer's role
- Facilitate access
- Support communication
- Enable staff to document carer involvement

This standard must be applied consistently across wards.

8.5 Safety and Quality Standards

8.5.1 Monitoring and Reducing Avoidable Harm

Trusts must track, monitor, and report dementia-related:

- Falls
- Malnutrition and dehydration incidents
- Prolonged distress episodes
- Medication errors
- Hospital-acquired infections and ulcers
- Delayed discharge
- Unnecessary restraint or sedation

Trusts must demonstrate actions taken to reduce harm trends.

8.5.2 Early Escalation of Concerns

Staff must have clear processes to escalate concerns about the safety or wellbeing of people with dementia. These processes must be:

- Known to all staff
- Supported by the Dementia Safety Lead
- Monitored for effectiveness

Carers must also have a route to raise concerns.

8.6 Discharge and Continuity Standards

8.6.1 Integrated Discharge Planning

Discharge for people with dementia must include:

- Early planning
- Involvement of carers
- Clear communication with community services
- Medication review
- Support for continued hydration, nutrition, and mobility
- A written summary tailored to the person's cognitive needs

8.6.2 Prevention of Unsafe Discharge

No person with dementia is to be discharged:

- Late at night
- Without a safe environment confirmed
- Without carer communication
- Without clear follow-up

This is a patient safety requirement, not an operational preference.

8.7 Summary

These standards define the minimum expectations NHS hospitals must meet under Elizabeth's Wish. They are designed to ensure that every person with dementia receives:

- Safe care
- Compassionate support
- Effective communication
- Skilled workforce involvement
- Carer partnership
- Coordinated discharge
- A hospital experience that preserves dignity and wellbeing

The following sections of the policy will outline roles, monitoring mechanisms, implementation timelines, and enforcement.

Section 9 - Roles and Responsibilities

This section sets out the responsibilities of all key stakeholders involved in delivering Elizabeth's Wish. Clear accountability ensures that dementia care is embedded at every level of hospital governance, leadership, and practice.

9.1 Trust Board and Executive Leadership

The Board is ultimately accountable for the delivery of dementia care standards. Responsibilities include:

- Assigning a Board-level Executive Lead for Dementia.
- Ensuring the Trust has a Dementia Strategy that is approved, reviewed annually, and publicly available.
- Monitoring implementation of mandatory training across all staff groups.
- Receiving quarterly reports on dementia care performance and incident trends.
- Ensuring that capital and operational planning includes dementia-friendly environments and resources.
- Supporting a culture of learning, reflection, and compassionate care across the organisation.

The Board must treat dementia care as a core patient safety priority, equivalent to infection control or safeguarding.

9.2 Dementia Safety Lead

A senior officer responsible for operational oversight of dementia care. Key responsibilities include:

- Coordinating strategy implementation and training delivery.
- Monitoring staff competence and confidence.
- Overseeing carer partnership programs and access systems.
- Ensuring compliance with clinical and environmental standards.
- Conducting regular audits and reporting findings to the Board.
- Acting as a point of liaison with ICBs, NHS England, and CQC.

The Dementia Safety Lead must have the authority to influence decisions across the Trust.

9.3 Ward and Department Leadership

Nurse managers, senior clinicians, and department leads are responsible for:

- Ensuring staff under their supervision receive role-appropriate dementia training.
- Implementing person-centred care plans consistently.
- Monitoring ward-level performance metrics, including safety incidents and carer involvement.
- Identifying environmental risks and making recommendations for improvements.
- Supporting staff to escalate concerns about patient safety or quality of care.

9.4 Clinical and Allied Health Staff

All clinical staff have a duty to:

- Apply person-centred care approaches in daily practice.
- Recognise and respond to distress or behavioural expressions.
- Involve carers in care planning and communicate effectively.
- Conduct assessments for delirium, hydration, nutrition, mobility, and pain.
- Escalate safety concerns promptly to ward leadership or Dementia Safety Lead.

All staff must complete and maintain their role-specific dementia training.

9.5 Non-Clinical Staff and Volunteers

Non-clinical staff and volunteers are critical to the patient experience. Responsibilities include:

- Engaging with patients respectfully and safely.
- Supporting orientation, signage, and environmental clarity.
- Reporting observed safety concerns or distress to clinical teams.
- Completing basic dementia awareness training.
- Supporting carer involvement where appropriate.

9.6 Carers

Carers are recognised as partners in care. Responsibilities include:

Providing information about personal routines, preferences, and history.
Supporting staff in daily care activities if appropriate.
Acting as advocates for the person with dementia when needed.
Communicating observations and concerns regarding wellbeing or safety.

Trusts must provide carers with support, clear access, and escalation routes.

9.7 Integrated Care Boards (ICBs)

ICBs have a system-level responsibility to:

- Monitor Trust-level compliance with dementia standards.
- Support training provision and workforce development.
- Facilitate integration with community dementia pathways.
- Escalate persistent non-compliance or quality concerns to NHS England.
- Promote sharing of best practice and learning across the region.

9.8 NHS England and Regulatory Oversight

NHS England will:

- Issue guidance and frameworks supporting Elizabeth's Wish.
- Monitor regional and national compliance trends.
- Collaborate with CQC to ensure dementia standards are reflected in inspections.
- Support policy evaluation and national reporting.

CQC will incorporate dementia care into inspection domains, using data, audits, and feedback to evaluate Trust compliance.

9.9 Summary

Each level of the system, from national bodies to front-line staff and carers, has clearly defined responsibilities under Elizabeth's Wish. Accountability, consistent application of standards, and partnership with carers are central to achieving the strategic objectives outlined in Section 8.

The next step is to define how compliance and performance will be measured, which will form the next section on monitoring, reporting, and enforcement.

Section 10 - Monitoring, Reporting and Enforcement

This section outlines how NHS Trusts, Integrated Care Boards (ICBs), NHS England, and the Care Quality Commission (CQC) will monitor, measure, and ensure compliance with the standards set out in Elizabeth's Wish. The purpose is to establish a transparent and robust framework that supports improvement while ensuring accountability across the system.

10.1 Overview of the Monitoring Framework

Monitoring will follow a three-tier system:

1. Trust-level internal monitoring, regular data collection, ward assurance processes, and Board reporting.
2. ICB and system-level oversight, reviewing Trust performance and addressing variation.
3. External regulation and national reporting, CQC inspections and NHS England oversight.

This integrated approach ensures that dementia care quality is visible, measurable, and continuously improving.

10.2 Trust-Level Monitoring Requirements

Each Trust must establish a formal monitoring process that includes the following:

10.2.1 Quarterly Dementia Performance Reports

Trusts must submit quarterly reports to their Board including:

- Dementia training compliance
- Incident trends involving people with dementia
- Carer involvement metrics
- Delirium screening rates
- Length-of-stay data
- Readmission rates
- Complaints and compliments
- Audit outcomes
- Progress on environmental improvements

These reports must be reviewed by the Executive Lead for Dementia.

10.2.2 Annual Dementia Care Audit

Trusts must conduct a comprehensive annual audit covering:

- Adherence to mandatory standards
- Effectiveness of care pathways
- Quality of person-centred care planning
- Workforce competence
- Carer experience and involvement
- Safety outcomes
- Discharge quality
- Compliance with environmental standards

Audit results must inform the annual review of the Trust's Dementia Strategy.

10.2.3 Incident and Risk Monitoring

All incidents involving people with dementia (e.g., falls, malnutrition, prolonged distress, medication errors) must be:

- Recorded consistently
- Reviewed promptly
- Analysed for learning
- Reported through governance systems
- Used to inform quality improvement plans

10.3 Carer and Patient Feedback Mechanisms

Trusts must implement structured feedback processes, including:

- Real-time feedback options for carers
- Post-discharge experience surveys
- Involvement of people with dementia and carers in governance groups
- Regular listening events or forums

Feedback must be used proactively to identify trends and improvements.

10.4 ICB Monitoring Responsibilities

Integrated Care Boards must:

- Review Trust-level performance reports
- Identify unwarranted variation between hospitals
- Support training coordination across the system
- Ensure alignment between hospital and community dementia services
- Escalate persistent concerns to NHS England when required

ICBs are responsible for regional oversight and for ensuring the system works as a whole.

10.5 CQC Inspection and Regulatory Enforcement

CQC will incorporate dementia standards into relevant inspection domains, including:

- Safe – prevention of avoidable harm, staff competence, risk management
- Effective – assessments, care planning, delirium management, training
- Caring – dignity, communication, emotional support
- Responsive – carer involvement, reasonable adjustments, safe discharge
- Well-led – governance, strategy implementation, culture

CQC inspectors will evaluate:

- Audit results
- Training compliance
- Carer involvement evidence
- Ward practices
- Staff interviews
- Documentation quality
- Environmental standards

Failure to meet standards may result in recommendations, conditions on the Trust, or regulatory action.

10.6 NHS England National Oversight

NHS England will:

- Collate national data from Trusts and ICBs
- Publish an annual national dementia care report
- Identify areas requiring support or intervention
- Provide guidance, tools, and best-practice examples
- Monitor long-term trends in safety, experience, and outcomes

NHS England may intervene where systemic issues persist.

10.7 Performance Metrics and Outcomes Framework

To ensure consistent monitoring, a national outcomes framework will be established. Trusts must track:

Safety

- Falls among people with dementia
- Delirium incidence
- Dehydration/malnutrition incidents
- Avoidable distress episodes
- Medication errors

Experience

- Carer satisfaction
- Communication quality
- Involvement in decision-making

Effectiveness

- Training compliance
- Adherence to care standards
- Discharge timeliness and quality

Equity

- Variation between wards, services, and Trusts
- Access to carers as partners in care

These metrics will form part of quality reporting and inspection.

10.8 Enforcement Mechanisms

Where standards are not met, the following actions may be taken:

- Formal recommendations from CQC
- Action plans monitored by Trust Boards
- Enhanced monitoring from ICBs
- Targeted support or intervention by NHS England
- Increased frequency of inspection
- Restrictions or conditions on the Trust
- Public reporting of persistent non-compliance

The approach balances support for improvement with accountability for safety and dignity.

10.9 Transparency and Public Accountability

To ensure public confidence, Trusts must publish:

- Their annual dementia audit
- Dementia training compliance figures
- Strategic plans and progress updates
- Outcomes from CQC inspections related to dementia care

This supports openness, learning, and trust between hospitals and the communities they serve.

10.10 Summary

The monitoring and enforcement framework ensures that Elizabeth's Wish is not simply a set of aspirations, but a fully accountable, measurable, and transparent policy with clear oversight. Through Trust-level audits, system-level coordination, and robust external regulation, the NHS will be able to demonstrate continual improvement in dementia care safety, dignity, and effectiveness.

Section 11 - Implementation Plan and Timescales

This section outlines the phased plan for introducing Elizabeth's Wish across all NHS hospitals in England. The aim is to ensure a manageable, coordinated, and accountable rollout that supports Trusts to embed new standards while maintaining service stability.

The implementation plan is built around three principles:

1. Achievability, changes must be practical within existing NHS structures.
2. Transparency, progress must be measurable and reportable.
3. Sustainability, improvements must be embedded permanently into NHS culture and governance.

11.1 Implementation Phases

The implementation of Elizabeth's Wish will follow a four-phase national framework.

Phase 1: National Launch and Preparation (Months 0–3)

Key Actions

- DHSC and NHS England formally publish Elizabeth's Wish as a national programme.
- Appointment of a National Dementia Hospital Care Lead within NHS England.
- Trusts identify and appoint their Executive Lead for Dementia.
- Initial communication packs issued to Trusts, ICBs, and stakeholders.
- CQC prepares updated inspection criteria reflecting the new standards.

Outputs

- National awareness created.
- Leadership structures in place.
- Clear expectations communicated.

Phase 2: Trust-Level Strategy Development (Months 3–9)

Key Actions

- Every NHS Trust must develop or refresh their Dementia Care Strategy.
- Strategies must detail:
    - Training rollout plans
    - Workforce preparedness
    - Environmental adaptations
    - Carer involvement systems
    - Governance structure

- Trusts complete baseline assessments against each mandatory standard.
- Initial training gap analysis conducted.
- ICBs begin regional oversight planning.

Outputs

- All Trusts have a localised blueprint for delivery.
- Baseline performance data gathered.

Phase 3: Implementation Across Trusts (Months 9–24)

Training

- Mandatory dementia training rolled out.
- Specialist training delivered to key departments (frailty, ED, AMU, wards).
- Non-clinical staff complete awareness modules.

Environment

- Low-cost environmental improvements prioritised first (signage, clocks, colour contrast).
- Plans developed for longer-term capital works.

Systems

- Carer access protocol implemented.
- Person-centred care documentation introduced.
- Dementia audit tools standardised.

Governance

- Trusts begin quarterly reporting to Boards.
- Results shared with ICBs and NHS England.

Outputs

- National standards embedded in routine practice.
- Training compliance reaching national targets.
- Carer partnership systems operational.

Phase 4: Consolidation, Monitoring, and National Reporting (Months 24–36)

Key Actions

- Annual audits conducted for two consecutive years.
- CQC assesses compliance under updated frameworks.
- NHS England publishes national outcome data.
- Trusts address any areas of persistent non-compliance.
- Strengthening of cross-Trust learning networks.

Outputs

- National consistency.
- Demonstrated improvements in safety and experience.
- Long-term sustainability plan established.

11.2 Implementation Timelines (Summary Table)

Timeline	National Actions	Trust Actions	Regulator Actions
0-3 months	Launch programme; appoint national leads	Appoint Executive Lead	Update CQC criteria
3-9 months	Issue detailed guidance	Develop dementia strategy; baseline assessments	Begin monitoring
9-24 months	Support rollout; collate reports	Implement training, systems, environmental changes	Early inspections
24-36 months	Publish national outcomes	Consolidate and improve	

11.3 Trust-Level Implementation Requirements

Each Trust must produce a detailed Implementation Delivery Plan covering:

- Workforce planning and training timelines
- Resource allocation
- Executive accountability
- Milestones and deadlines
- Audit and progress monitoring
- Carer involvement integration

Trusts must demonstrate how changes will be sustained beyond the initial rollout.

11.4 System-Level Responsibilities

Integrated Care Boards

ICBs must:

- Oversee regional consistency
- Facilitate shared training resources
- Support struggling Trusts
- Monitor progress quarterly

NHS England

NHS England must:

- Publish national guidance
- Provide templates, tools, and training frameworks
- Evaluate national performance
- Coordinate improvement programmes

Care Quality Commission

CQC must:

- Assess adherence to mandatory standards
- Include dementia metrics within inspection reports
- Enforce compliance where needed

11.5 Staff and Carer Engagement During Implementation

Staff Engagement

Trusts must ensure staff are informed, supported, and involved through:

- Training
- Communication campaigns
- Feedback mechanisms
- Ward-level champions

Carer Engagement

Implementation must include:

- Co-design workshops
- Carer advisory groups
- Integration of feedback into strategy development

11.6 Risks and Mitigation

Common risks include:

- Workforce capacity pressures
- Variation in Trust readiness
- Resource limitations
- Environmental constraints

Mitigation strategies include:

- Phased training
- Targeted support from ICBs
- Flexible implementation models
- Prioritisation of high-impact, low-cost improvements

11.7 Post-Implementation Review

After 36 months:

- NHS England will conduct a formal evaluation of Elizabeth's Wish.
- A public report will outline progress, challenges, and outcomes.
- Recommendations will guide long-term national dementia strategy.

11.8 Summary

This establishes a practical, structured, and achievable plan for delivering Elizabeth's Wish across the NHS. It ensures the policy is not aspirational alone, but fully operational and integrated into Trust governance, workforce development, clinical practice, and regulatory oversight.

Section 12 - Evidence Base and Economic Rationale

There is a robust evidence base showing that dementia already places a very heavy and growing burden on UK health services, particularly hospitals, and that this burden will only grow without systemic changes. The data supports the urgent need for a comprehensive national dementia-care policy such as Elizabeth's Wish.

12.1 The National Burden of Dementia

- In 2024, the total annual cost of dementia in the UK, across health care, social care, unpaid care, lost productivity and quality-of-life costs, is estimated at £42 billion. [1]
- That cost is projected to almost double to £90 billion by 2040, as the number of people living with dementia increases. [1]
- Among these costs, healthcare accounts for a substantial portion. The most recent estimates show that secondary care (hospital-based care including inpatient stays, outpatient appointments, and A&E attendances) remains a significant component of overall dementia-related healthcare expenditure. [2]

These figures demonstrate that dementia is not only a clinical and social issue, it is already a major economic and health-system challenge.

12.2 Impact on Hospitals and Acute Services

- According to data from Alzheimer's Research UK, the cost of dementia on hospitals in England rose sharply from £1.2 billion in 2010/11 to £2.7 billion in 2017/18. [3]
- Over the same period, the number of dementia-related hospital admissions increased by 93% (from ~210,000 to ~405,000), and hospital bed-days for people with dementia rose from 6.3 million to 9.4 million. [3]
- Recent analysis shows that for unplanned (non-elective) admissions, people with dementia tend to stay significantly longer than comparable patients without dementia. [4]
- One key summary found that "people with dementia stay over twice as long for acute inpatient care compared to patients without dementia," especially for emergency admissions. [4]

In practical terms, this means dementia contributes massively to hospital bed occupancy, longer lengths of stay, higher resource use, and increased demand on acute services.

12.3 Strain on A&E, Emergency Admissions and Unplanned Care

- People with dementia, and particularly people with undiagnosed dementia, are significantly more likely to use emergency services. According to Alzheimer's Society, those with undiagnosed dementia are nearly three times as likely to attend A&E compared with people without dementia. [5]
- As the severity of dementia increases, the likelihood of longer hospital stays following unplanned admissions also rises sharply. [5]
- Without appropriate dementia-competent care, hospitals face heightened risks of complications, readmissions, extended stays, and more frequent emergency admissions, all of which translate into higher costs and pressure on NHS capacity. [2]

12.4 The Human and Systemic Cost of Poor Dementia Care

Beyond pure financial cost, poor dementia care in hospitals leads to:

- Increased risk of avoidable harm: complications, delirium, falls, dehydration, malnutrition, longer recovery times. [2]
- Greater distress and trauma for people with dementia and their families. [6]
- Higher carer burden, repeated hospital admissions, and preventable deterioration. [6]

- Inequities in care, depending heavily on which hospital or ward a person accesses. [6]

These human costs carry indirect economic impacts: pressure on carers (unpaid care), increased social care demand, lost productivity, mental health impacts, and long-term care needs. Since dementia already consumes a large share of national resources, preventing avoidable harm and improving care quality could yield significant cost savings over time. [1]

12.5 Why National Reform Is Essential

- The rising numbers: there are currently an estimated 982,000 people living with dementia in the UK, a number projected to grow significantly by 2040. [1]
- Given the steep rise in hospital admissions, bed-days, and associated costs for dementia patients, as shown in the 2017/18 data for England, piecemeal local policies are unlikely to be sufficient. [3]
- Structural change, including mandatory training, consistent standards, better environments, and carer involvement, is required to shift the entire system from reactive, emergency-driven care to prevention, dignity, and planned support. [2, 6]

Without national standards, many hospitals will continue to struggle, and inequalities in experience and outcomes will persist.

12.6 The Economic Rationale for Elizabeth's Wish

The evidence is clear: dementia already imposes a massive, growing burden on the NHS, especially on hospital services. Without intervention, this burden will increase significantly as the population ages and dementia becomes more prevalent.

Implementing a national, enforceable framework for dementia care, as proposed under Elizabeth's Wish, is not only morally and clinically justified, but also economically sensible. It stands to reduce avoidable harm, lower hospital pressures, improve patient and carer experiences, and potentially deliver long-term savings or resource efficiencies.

Given the data and projections, there is no credible alternative to systemic reform if the NHS is to serve people with dementia safely, humanely, and sustainably.

Section 13, Legislative and Policy Alignment

Elizabeth's Wish aligns directly with existing legislation, statutory duties, national strategies, and regulatory frameworks governing the NHS in England. The initiative strengthens, rather than duplicates, current requirements, ensuring that dementia care is delivered consistently, safely, and lawfully across all hospitals.

13.1 Alignment with the Health and Social Care Act 2012

The Health and Social Care Act establishes the legal duty of NHS England to improve quality and reduce inequalities. Elizabeth's Wish supports these statutory duties by:

- Addressing widespread variation in dementia care quality;
- Reducing avoidable harm among a vulnerable group with protected needs;
- Improving the integration of services for people with dementia and their carers;
- Enhancing the safety and experience of patients with cognitive impairment.

The policy also supports the Act's requirement for the NHS to involve patients and the public in service design and improvement.

13.2 Compliance with the Care Act 2014

The Care Act reinforces the importance of wellbeing, safeguarding, and carer involvement. Elizabeth's Wish strengthens compliance by:

- Formally recognising carers as partners in care;
- Ensuring carers receive appropriate information, support, and involvement in decisions;
- Preventing neglect, distress, and avoidable deterioration by embedding dementia-competent care;
- Promoting personalisation and dignity in acute settings.

13.3 Supporting the Mental Capacity Act 2005

People with dementia frequently fall under the protections of the Mental Capacity Act (MCA). This policy reinforces:

- Lawful assessment of capacity;
- Best-interest decision-making in partnership with carers;
- Reduced reliance on restrictive or inappropriate interventions;
- Improved staff understanding of consent, autonomy, and communication.

Mandatory training ensures that NHS staff fulfil their MCA responsibilities accurately and compassionately.

13.4 Alignment with the Equality Act 2010

Dementia is classified as a disability under the Equality Act. Elizabeth's Wish directly addresses the Act's requirements by:

- Ensuring reasonable adjustments, such as dementia-friendly environments;
- Improving accessibility of information and communication;
- Reducing discriminatory barriers to safe and effective care;
- Promoting equal treatment and safeguarding against disadvantage.

13.5 Strengthening the NHS Long Term Plan (2019)

The Long Term Plan calls for improved dementia care, more personalised care models, and better support for carers. Elizabeth's Wish delivers measurable implementation by:

- Providing a national programme of dementia training;
- Embedding person-centred approaches into hospital practice;
- Improving urgent and emergency pathways for people with dementia;
- Reducing avoidable hospitalisation and readmission.

This policy operationalises several commitments the NHS has not yet fully met.

13.6 Alignment with CQC Regulatory Framework

The Care Quality Commission assesses hospitals on safety, leadership, responsiveness, and person-centred care. Elizabeth's Wish aligns with these domains by:

- Creating enforceable standards for safe dementia care;
- Improving staff competencies and safeguarding practices;
- Reducing complaints and safety incidents linked to cognitive impairment;
- Strengthening governance and oversight.

Hospitals delivering poor dementia care risk failing inspections. This policy helps Trusts gain regulatory assurance.

13.7 Integration with NHS Patient Safety Strategy

People with dementia are statistically more vulnerable to falls, delirium, dehydration, and avoidable harm. Elizabeth's Wish supports the Patient Safety Strategy by:

- Targeting the highest-risk patient group with evidence-based prevention;
- Embedding safety culture improvements;
- Ensuring national monitoring and reporting;
- Reducing unwarranted variation in outcomes.

13.8 Fit with the Dementia 2020 and Dementia 2025 Frameworks

While many commitments from prior dementia strategies remain unmet, this policy:

- Provides a practical hospital-focused delivery mechanism;
- Ensures dementia is prioritised across acute care;
- Addresses training deficits identified in multiple national audits;
- Advances commitments to early identification, personalised care, and carer partnership.

Section 14 - Consultation and Stakeholder Engagement

Successful implementation of Elizabeth's Wish requires comprehensive engagement with the people who deliver, use, and support dementia care across the NHS. Stakeholder consultation ensures the policy is credible, evidence-based, and shaped by those with lived experience.

14.1 Core Stakeholders

Consultation will involve the following groups:

People Living With Dementia and Their Families

- Individuals with early-stage or lived experience of dementia
- Carers and relatives, including those affected by recent bereavement
- Advocacy groups and lived experience networks

Health and Care Staff

- Nurses, healthcare assistants, and ward staff
- Geriatricians, psychiatrists, and dementia specialists
- A&E, AMU, and frailty teams
- Hospital managers and clinical leads
- Allied Health Professionals
- Support services (porters, catering, estates, admin)

National Organisations

- Alzheimer's Society
- Alzheimer's Research UK
- Dementia UK
- Royal Colleges (Nursing, Physicians, Psychiatrists, Emergency Medicine)
- Care Quality Commission (CQC)
- NHS England and local Integrated Care Boards
- Health Education England / NHS Learning Hub (for training frameworks)

Voluntary and Community Sector

- Dementia charities
- Hospices and carers' centres
- Local dementia alliances

14.2 Consultation Activities

A structured consultation programme will include:

- Public consultation document published nationally
- Roundtable discussions with carers and people with lived experience
- Engagement workshops with NHS Trusts and ICBs
- Professional advisory panels with Royal Colleges
- Online survey for staff, carers, and voluntary sector partners
- Call for evidence from clinicians, researchers, designers, and hospital leaders
- Pilot-site testing in 3–5 hospitals to gather real-world feedback

This ensures the policy meets real needs and reflects frontline realities.

14.3 Incorporating Feedback

Stakeholder feedback will inform:

- Refinements to dementia training content
- Environmental assessment tools
- Carer involvement protocols
- Data-collection and reporting frameworks
- Timelines and feasibility considerations
- Required support for Trusts at different maturity levels

A formal Consultation Response Report will be published summarising findings and changes.

14.4 Ongoing Engagement

Engagement does not end after launch. Ongoing involvement will include:

- Annual patient and carer experience surveys
- A national lived-experience advisory group
- Regular staff listening events
- Continuous feedback loops through CQC and ICB oversight
- Transparent public reporting on progress

Section 15 - Expected Benefits and Outcomes

Elizabeth's Wish is designed to deliver measurable improvements in safety, quality, and experience for people living with dementia in NHS hospitals. This section outlines the clinical, operational, financial, and societal outcomes expected from full implementation.

15.1 Improved Patient Safety

People with dementia are disproportionately impacted by avoidable harm in hospitals. The programme is expected to achieve:

- Reduction in inpatient falls, supported by international evidence showing dementia training can reduce falls by up to 30% [7].
- Lower rates of hospital-acquired delirium, a major cause of prolonged stays and mortality [7].
- Improved hydration and nutrition, reducing risk of kidney injury, pressure injury, and infection [8].
- Safer use of medication, through better recognition of pain, agitation, and behavioural symptoms [8].
- Reduced use of restrictive practices, including sedatives and constant observation, by improving de-escalation and communication skills [9].

These outcomes collectively reduce harm and save lives.

15.2 Reduced Length of Stay and Faster Recovery

- Evidence shows that people with dementia generally stay two to three times longer in hospital than other patients, often because their cognitive needs aren't met [4].
- Expected outcomes include shorter inpatient stays, fewer delayed discharges, and reduced emergency readmissions [7,8].

15.3 Enhanced Patient and Carer Experience

- Trust and dignity are core drivers of this policy. Implementation will lead to:
    - More compassionate, person-centred care from a better-trained workforce [9].
    - Greater involvement of carers, who are treated as partners rather than visitors [10].
    - Clearer communication, ensuring families are informed, included, and respected [10].
    - Reduced distress, fear and confusion among patients due to improved environments and staff confidence [8].
    - More personalised care planning, reflecting the patient's history, preferences, and routines [9].

15.4 Workforce Confidence and Capability

- The policy strengthens NHS workforce capability by ensuring all staff receive dementia-specific training. Expected benefits include:
    - Increased staff confidence in supporting communication, behaviours, and complex care needs [9,11].
    - Reduced stress and burnout by equipping staff with practical strategies to manage challenging situations [9].
    - A consistent national standard, ensuring competence across all Trusts [11].
    - Better interdisciplinary working, as dementia is embedded across all clinical teams [9].
    - Clear accountability structures, supporting professional development and safer practice [11].

15.5 Operational and System-Level Benefits

• By improving dementia care across hospitals, the policy strengthens the whole system:

- Reduced demand on A&E and urgent care through fewer unnecessary admissions [7].
- Improved hospital flow, with reduced length of stay and fewer discharge delays [4,7].
- Better utilisation of inpatient beds, benefiting capacity management [7].
- Greater efficiency, freeing clinical time previously absorbed by preventable crises or behavioural distress [8].
- Stronger integration across services, improving transitions between hospital, community care, and primary care [10].

15.6 Financial Benefits and Cost Avoidance

Evidence from national and international studies demonstrates clear economic value:
• Shorter inpatient stays reduce costs associated with prolonged admissions [7].
• Fewer falls, infections, and delirium episodes prevent expensive harm events [7,8].
• Reduced constant observation ("specialising") leads to measurable savings [9].
• Less need for agency staff, as teams become more confident and efficient [11].
• Avoided readmissions reduce pressure on acute budgets [7,10].

Investing in dementia training and environmental improvement yields significant long-term savings for the NHS.

15.7 Reduced Inequalities and Improved Legal Compliance

The policy strengthens the NHS's ability to meet statutory duties under the:

- Equality Act 2010
- Mental Capacity Act 2005
- Care Act 2014
- Health and Social Care Act 2012

Expected outcomes include:

• Safer care for a legally protected group [11]
• Fewer safeguarding incidents [10]
• Improved compliance with CQC requirements [11]
• More consistent national standards, reducing postcode variation [9]

This ensures the NHS meets its obligations to protect vulnerable patients.

15.8 Long-Term Societal Benefits

Beyond hospital settings, the policy delivers wider social value:

• Reduced pressure on carers, who often experience emotional and physical strain [10].
• Greater confidence in the NHS, improving public trust [7].
• Better quality of life for people with dementia, even after discharge [8].
• A more dementia-friendly society, through visible leadership and cultural change [9].
• Public reassurance that hospital care will be safe, compassionate, and competent [10].

Section 16 - Conclusion and Call to Action

16.1 Summary of Need

- Dementia represents a significant and growing burden on patients, carers, and the NHS [1–11].
- Hospitals face demonstrable challenges in delivering safe, effective, and person-centred care, despite existing statutory duties and national strategies [12–15].

16.2 Key Outcomes of Elizabeth's Wish

- Improved patient safety: fewer falls, delirium episodes, and avoidable harm [7–9].
- Enhanced patient and carer experience: dignified, compassionate care with active family involvement [10].
- Stronger workforce capability: confident, trained staff delivering consistent dementia-competent care [9,11].
- Operational and financial benefits: shorter length of stay, reduced readmissions, and cost avoidance [7, 8, 9, 10,11].

16.3 Urgency for Implementation

- The prevalence of dementia is rising, hospital admissions are increasing, and current variation in care contributes to avoidable harm and inefficiency [1–6].
- Without a national, enforceable framework, these problems are likely to worsen, placing additional strain on the NHS and carers.

16.4 Call to Action

- NHS Trusts, Integrated Care Boards, and the Department of Health & Social Care should adopt Elizabeth's Wish as a mandatory standard for acute care.
- MPs are urged to support this initiative, ensuring that hospitals are accountable for implementing dementia strategies, training staff, and embedding person-centred, safe care.
- Monitoring and reporting frameworks should be established to track progress, outcomes, and compliance.

16.5 Final Statement

Elizabeth's Wish is not only a moral and clinical imperative, but a practical, evidence-based solution to a national problem. Adoption would save lives, improve quality of care, reduce inequalities, and strengthen the NHS.

Immediate action is required to ensure that people living with dementia receive the care, dignity, and protection they deserve.

15.9 / 16.6 References

1. Alzheimer's Society. Dementia in the UK: scale, impact and numbers. 2024. Available at: https://www.alzheimers.org.uk/what-we-do/policy-and-influencing/dementia-scale-impact-numbers

2. Dementia Researcher / NIHR. The annual costs of dementia in the UK: updated estimates. 2024. Available at: https://www.dementiaresearcher.nihr.ac.uk/wp-content/uploads/2024/05/the-annual-costs-of-dementia-1.pdf

3. Alzheimer's Research UK. Cost of dementia to hospitals in England doubles. 2019. Available at: https://www.alzheimersresearchuk.org/news/cost-of-dementia-hospitals-england-doubles/

4. Alzheimer's Society. Dementia and the contribution to health metrics. 2024. Available at: https://www.alzheimers.org.uk/sites/default/files/2024-09/Dementia-contribution-health-metrics.pdf

5. Alzheimer's Society. Living with undiagnosed dementia: three times more likely to visit A&E. 2024. Available at: https://www.alzheimers.org.uk/news/2024-09-16/living-with-undiagnosed-dementia-three-times-more-likely-visit-ae

6. Carers UK. State of Caring Report. 2023. Available at: https://www.carersuk.org/news-and-campaigns/press-releases

7. Morris M.E., et al. Interventions to reduce falls in hospital settings: systematic review. Age and Ageing, 2019.

8. Hshieh T., et al. Effectiveness of multi-component delirium prevention programmes: systematic review and meta-analysis. BMJ, 2015.

9. Abraham J., et al. Interventions for preventing and reducing the use of physical restraint in older people. Cochrane Database of Systematic Reviews, 2018.

10. Coleman E.A., et al. Effects of caregiver-oriented transitional care interventions on hospital readmissions. Journal of the American Geriatrics Society, 2006.

11. Gkioka M., et al. Evaluation and Effectiveness of Dementia Staff Training. International Journal of Older People Nursing, 2019.

About the Author

Nathan Weedon is a HCPC registered paramedic with over 12 years of frontline experience as an ambulance clinician, delivering care across diverse emergency and urgent care settings. He has a strong professional and personal commitment to dementia care, informed by both clinical experience and lived experience with the condition.

Nathan graduated with a First-Class Honours degree from the University of Cumbria, where his research and critical analysis based dissertation titled “Unlocking Innovation: Navigating Pre-hospital Dementia Care with Assistive Technology - A Comprehensive Review of the implementation and uses of Assisted Technology for Enhancing Pre-hospital Dementia Care” focused on the pre-hospital assessment and care of people living with dementia, highlighting the importance of early recognition, tailored interventions, and safe transitions into hospital care.

A dedicated dementia advocate, Nathan works to improve awareness, training, and standards within the ambulance service, ensuring that people with dementia and their families receive safe, compassionate, and dignified care. Through his combined expertise in frontline practice, research, and advocacy, Nathan seeks to influence policy and practice to enhance outcomes for patients living with cognitive impairment.