

Elizabeth's Wish

Ending Avoidable Harm for People with
Dementia



www.elizabethswish.com

Introducing Elizabeth's Wish

She deserved safety. She deserved dignity. She deserved better

Elizabeth was a mother, grandmother, and much-loved woman living with dementia. When she went into the hospital, her family trusted she would be safe, but basic dementia-aware practices weren't followed. Her confusion escalated, her needs were missed, and her avoidable deterioration led to her death.

Her story is not unique. Every year, hundreds of thousands of people with dementia enter UK hospitals. Many experience fear, distress, delirium, malnutrition, falls, or avoidable complications, not because staff don't care, but because the system doesn't prepare them.

Elizabeth's Wish exists for one purpose:

To ensure no family ever loses someone they love because a hospital wasn't equipped to care for dementia

Elizabeth's Wish calls for clear, practical, evidence-based reforms



Mandatory Training

The introduction of mandatory training ensures consistent, safe, accountable care



Patient Passport

Collecting essential details and involving caregivers to prevent avoidable harm and distress



Accountability

Hospitals would be required to demonstrate compliance with dementia-competent care, ensuring families no longer rely on luck



Environmental Changes

Changes to lighting, signage, noise levels, and layout to reduce agitation, falls, and confusion

Why Change is Needed

Dementia is one of the UK's greatest healthcare challenges, but hospitals are not yet dementia-safe.

982,000

It's estimated that 982,000 people are living with dementia in the UK (2024) [1]

- England recorded 482,978 people with a formal dementia diagnosis in Dec 2024 [2]
- A significant proportion of all unscheduled hospital admissions involve people living with dementia [3]
- NICE guidance states hospitals must adapt environments, communication, and care plans for people with dementia, yet compliance is inconsistent nationwide [4]

What's going wrong?

National reviews show gaps in:

- Staff training (clinical and non-clinical)
- Environmental safety
- Communication with families
- Early detection of delirium
- Understanding behavioural distress
- Consistent accountability across Trusts

Impacts of inadequate dementia care:

People living with dementia face higher rates of:

- Delirium
- Falls
- Use of restraints or sedatives
- Poor nutrition and hydration
- Longer lengths of stay
- Family distress and loss of trust

These are not inevitable.

They are preventable, with the right training, systems, and standards

Families feel powerless and patients get lost in the system

"We weren't listened to"

"Nobody explained what was happening"

"They didn't know what 'normal' looked like for her"

"She deteriorated so fast. It was avoidable"

[1] Alzheimer's Society – Prevalence 2024 <https://www.alzheimers.org.uk>

[2] NHS England – Dementia Diagnosis Monthly Stats 2024 <https://digital.nhs.uk/data-and-information>

[3] NHS England – Dementia and Hospital Care <https://www.england.nhs.uk>

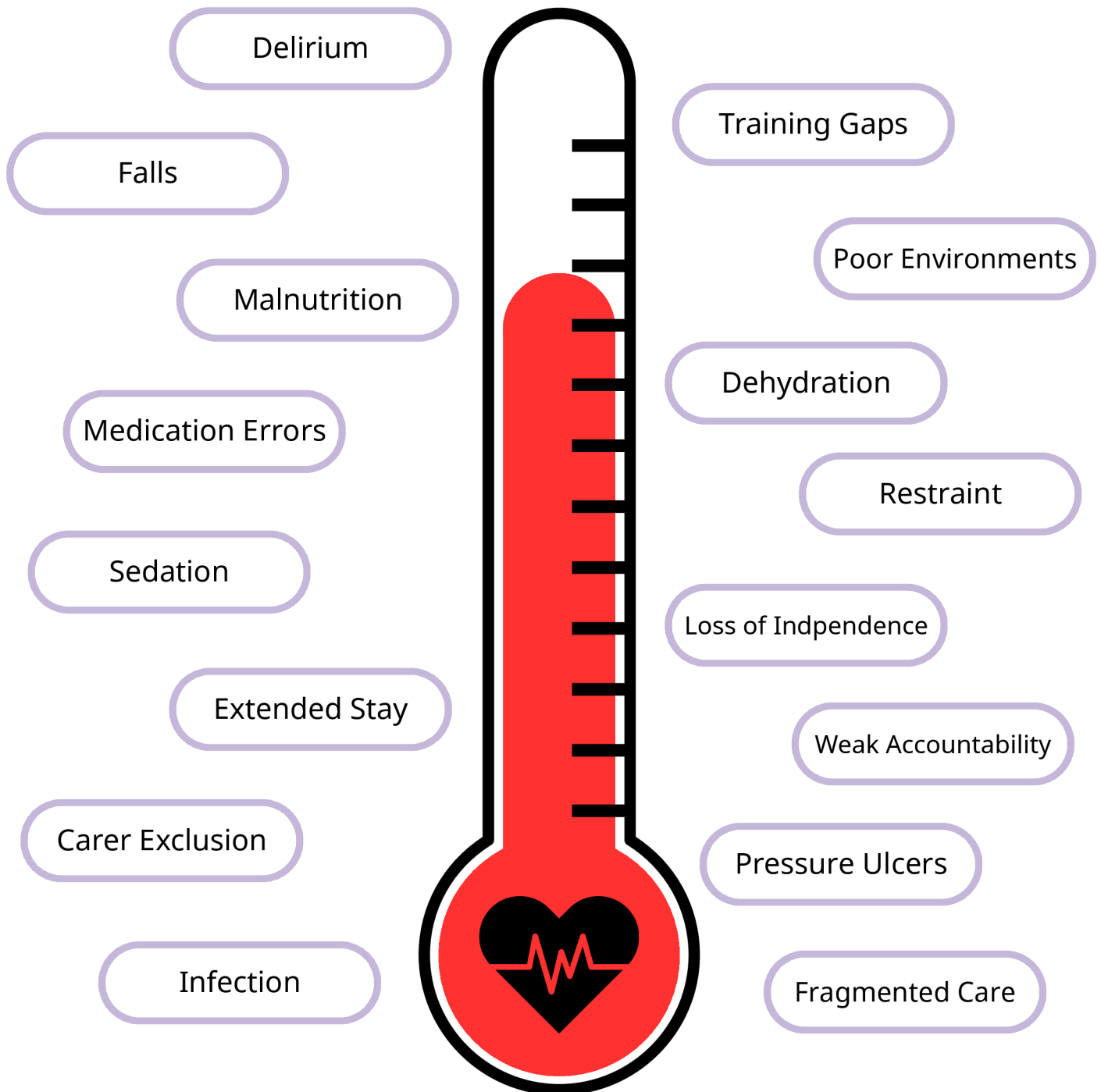
[4] NICE Guideline NG97 – Dementia Assessment, Management and Support <https://www.nice.org.uk/guidance/ng97>

[5] NICE and HEE Dementia Training Standards Framework <https://www.skillsforhealth.org.uk>

The Risks

What if the system meant to protect your loved one actually puts them at risk?

People living with dementia face higher hospital risks when compared to other patients, meaning they are more likely to experience:



Many of these harms are preventable with trained staff and dementia-friendly systems

Would you feel safe leaving your loved one in a system that isn't prepared to meet their most basic needs? If this were your parent, would 'good enough' still be good enough?

The Cost of Poor Care

Every unrecognised symptom, every missed cue, and every preventable decline translates to real, lasting harm, harm that affects patients long after discharge

Failing to act is not neutral. In dementia care, doing nothing has a measurable human, clinical, and financial cost and that cost grows with every hospital admission

Human Cost

When staff are untrained, systems are unprepared, and environments are not dementia-aware, patients experience:

- Avoidable distress, fear, and confusion
- Increased delirium, leading to prolonged admissions
- Breakdown of mobility and independence
- Malnutrition and dehydration when needs aren't recognised
- Higher risk of falls, infections, and pressure injuries
- A loss of dignity in moments that should be protected



Family Cost

Inaction does not only affect the patient. Families pay the price too:

- Trauma from witnessing poor-quality care
- Breakdown of trust in NHS services
- Increased carer burden following avoidable decline
- Emotional distress knowing their loved one was unsafe
- Families remember these moments for life



System Cost

Inaction creates an expensive cycle that strains already pressured NHS services:

- Longer hospital stays caused by preventable complications
- Higher readmission rates
- Increased safeguarding investigations
- Greater staffing pressures due to behavioural distress
- More complaints, litigation, and reputational risk



The Simple Truth

The cost of doing nothing is always higher than the cost of doing better.

Hospitals pay for inaction in beds. Families pay for inaction in grief.

Patients pay for inaction in decline.

And when the system isn't prepared, the most vulnerable lose the most

Ethical Implications

Every unrecognised symptom, every missed cue, and every preventable decline translates to real, lasting harm, harm that affects patients long after discharge

Do No Harm

Healthcare systems have a fundamental obligation to do no harm. But dementia patients encounter: Heightened fear and confusion. Preventable injuries. Miscommunication and unmet needs. Delays in treatment or mismanagement of symptoms. Staff receive minimal training but are not held to account if they fail to implement it



Standards of Care



People living with dementia deserve the same standard of care as any other patient group. Yet the lack of training, adapted pathways, and specialist oversight creates a two-tier system: One for those who can clearly communicate, self-advocate, and understand hospital processes and one for those who cannot

Moral Choices

Hospitals are morally accountable for environments and policies that predictably cause harm. If a system knows: that dementia prevalence is rising, that admissions are frequent, and that outcomes worsen without tailored care, then inaction is an ethical choice, one that undermines professional standards and public trust



Advocacy

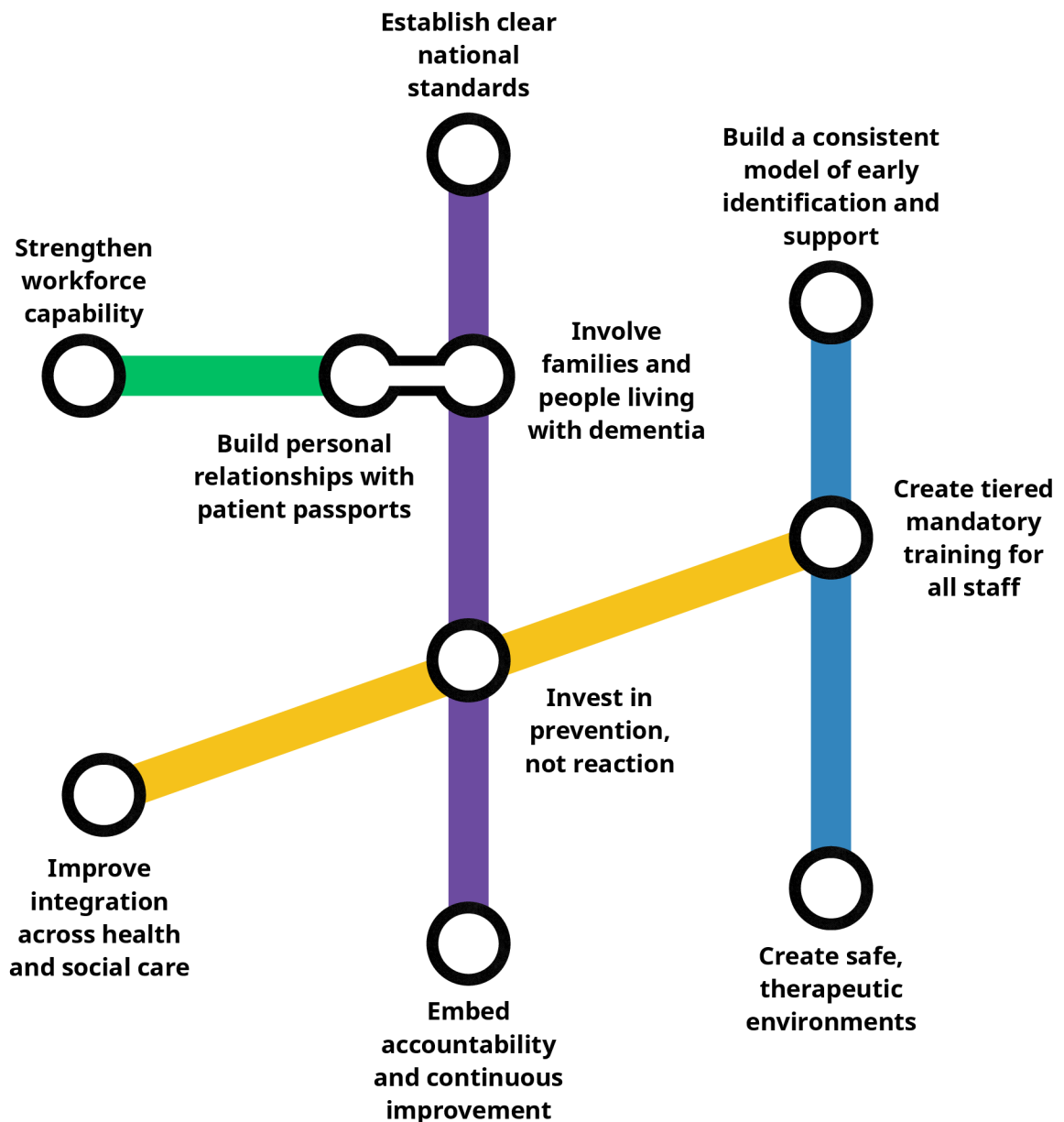


How we treat those who cannot advocate for themselves reflects who we are as a society. Right now, too many people with dementia experience: Fear instead of reassurance. Confusion instead of clarity. Isolation instead of connection. Risk instead of safety. Ethically, this is indefensible

Without reform now, harm will increase.
With the right national policy, outcomes improve immediately. When a system is unprepared for dementia, it is not merely inefficient; it is unethical

The Pathway to Change

Improving dementia care does not require reinventing the system, it requires aligning what we already know works into a clear, coordinated pathway. The actions needed are simple, evidence-based, and achievable. By organising these steps into a national approach, we can deliver safer, more consistent, and more dignified care for people living with dementia.



A Pathway that Works for Everyone

A national dementia pathway would provide people with dementia safer care and a better quality of life, families' confidence and involvement, professionals the tools and support they need, whilst reducing the pressure on the system, leading to fewer crises and more sustainable costs

This is not just a policy shift; it is a commitment to dignity, accountability, and smarter care

Get Involved

Change only happens when people demand it. This is your moment to make a difference

Elizabeth's Wish is now moving into the public phase and we need your voice.
Sign the government petition

We are calling on the UK Government to:

- Introduce mandatory dementia-specific hospital standards
- The introduction of mandatory staff training for all levels of staff
- Standardised care plans and the use of the 'Elizabeth's Wish Patient Passport'
- Staff and Trust-level accountability measures

Your signature helps demonstrate to Parliament that this reform is necessary, achievable, and urgent.

Why sign?

- Because dementia can affect any family
- Because patients deserve safety and dignity
- Because families deserve confidence, not fear
- Because Elizabeth's story should not be repeated

Share the campaign
Spread the word
Tell others
Start conversations
Your voice is powerful

Together, we can make hospitals safer for people living
with dementia and honour Elizabeth by changing the
future for every family

Learn More & Sign the Petition



WishforElizabeth



contact@elizabethswish.com



www.elizabethswish.com



Wish4Elizabeth