

Don't forget to join in the
conversations on twitter
Tweet us at **#quality2019**

B4 #qfb4



Healthcare
Improvement
Scotland

ihub

Improving co-ordination: Improving care Supporting people with dementia in the community

Lynn Flannigan

Improvement Advisor

Focus on Dementia

ihub

Healthcare Improvement Scotland

Lynn.Flannigan@nhs.net

[@lynnflannigan1](#)

Enabling health and
social care improvement

Declaration of interests

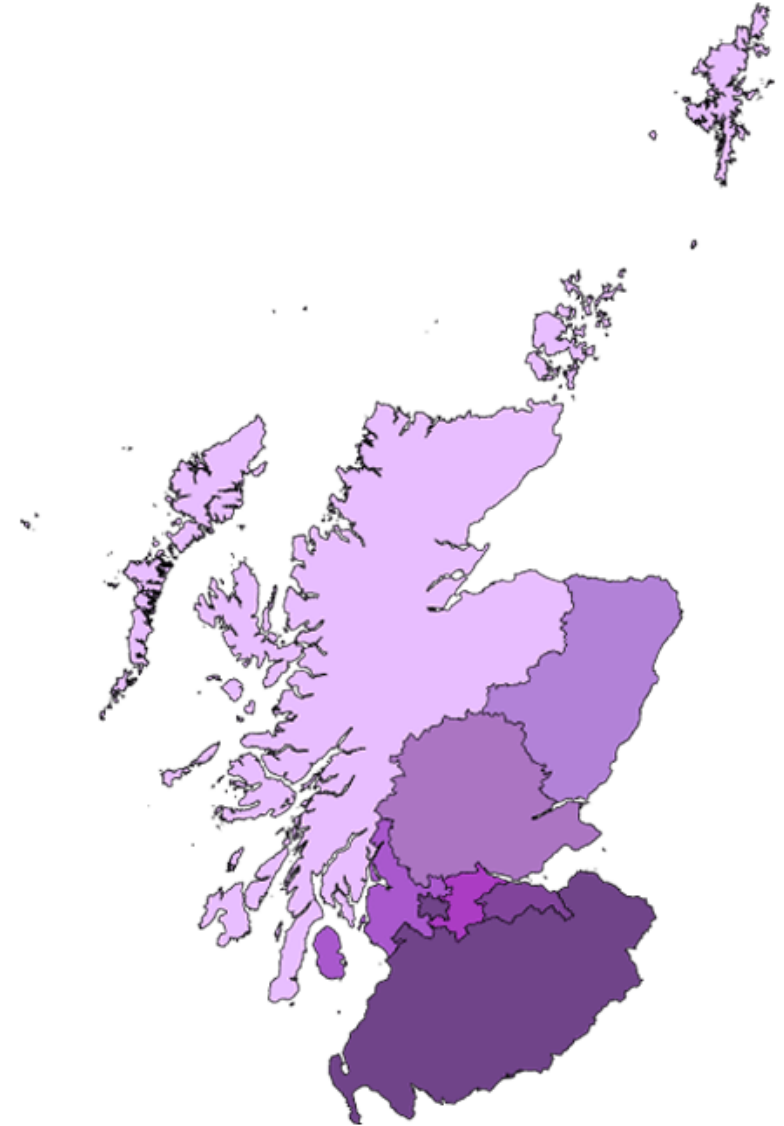
- I am employed by the NHS (Healthcare Improvement Scotland)
- The work we do is funded by the NHS and commissioned by the Scottish Government

Today's session

- Provide national dementia context
- Care co-ordination evidence base and approaches
- Focus on Dementia Portfolio
- Work, methodologies and key findings

Scottish Context for Dementia

- 5.2 million population
- 90,000 people with dementia
- 3,000 people under the age of 65
- Dementia priority since 2010
Third dementia strategy



Scotland's National Dementia Strategies 2010-2020

National Dementia Strategy 2010

- 8 Actions
- Charter of Rights – PANEL Principles
- Diagnosis and post diagnostic support
- Improving care in general hospitals
- Standards of care
- A Skills and Knowledge Framework



Standards of Care for Dementia in Scotland

Action to support the change programme,
Scotland's National Dementia Strategy

June 2011



National Dementia Strategy 2013

- 17 commitments
- Diagnosis and post diagnostic support – 5 Pillar Model
- Coordinated community care – 8 Pillar
- Acute care and other hospitals/NHS settings



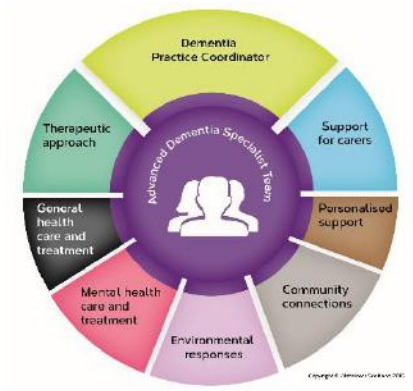
Copyright © Alzheimer Scotland 2013

National Dementia Strategy 2017

- 21 Commitments
- Timely, skilled and well-coordinated support – diagnosis to end of life
- Consistently person-centred and flexible
- On-going system re-design
- Palliative and end of life care



Copyright © Alzheimer Scotland 2017

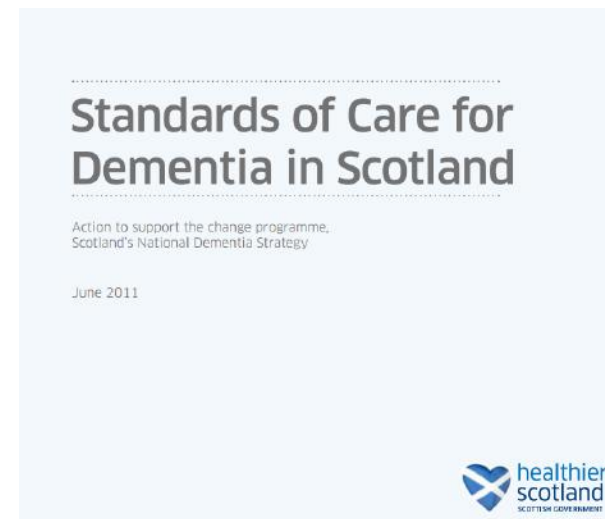


Copyright © Alzheimer Scotland 2017

A vision for dementia in Scotland

Our shared vision is of a Scotland where people with dementia and those who care for them have access to timely, skilled and well co-ordinated support from diagnosis to end of life which helps achieve the outcomes that matter to them.

Scottish Government, Dementia Strategy 2017-2020.



Healthcare Improvement Scotland



Many parts, one purpose -
better quality health and social care
for everyone in Scotland.

| Advice
on new
medicines

| Advice
on health
technologies

| Standards,
guidelines
and indicators

| Inspections
and reviews

| Enabling health
and social
care improvement

| Death
Certification
Review Service

| Scottish
Patient Safety
Programme

| Improving
antibiotics
use

| Making
the public
voice count

| Global quality
improvement
webinars

Focus on Dementia: Scotland's improvement programme for dementia

To Improve the quality and experience of care and support for people with dementia, staff and carers, supporting key commitments of Scotland's dementia strategy.



Diagnosis
and Post
Diagnostic
Support

Integrated
Care Co-
ordination

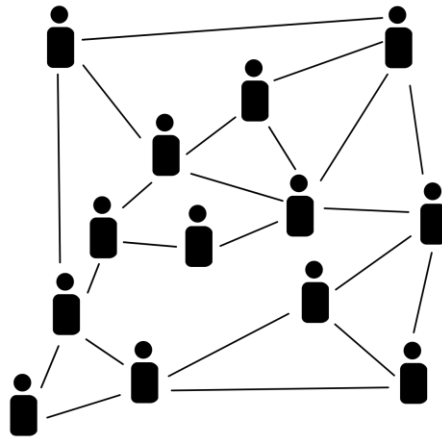
Advanced
Care

Primary Care, Community,
Acute Hospitals, Specialist Dementia Units

How we work



Demonstrator Sites



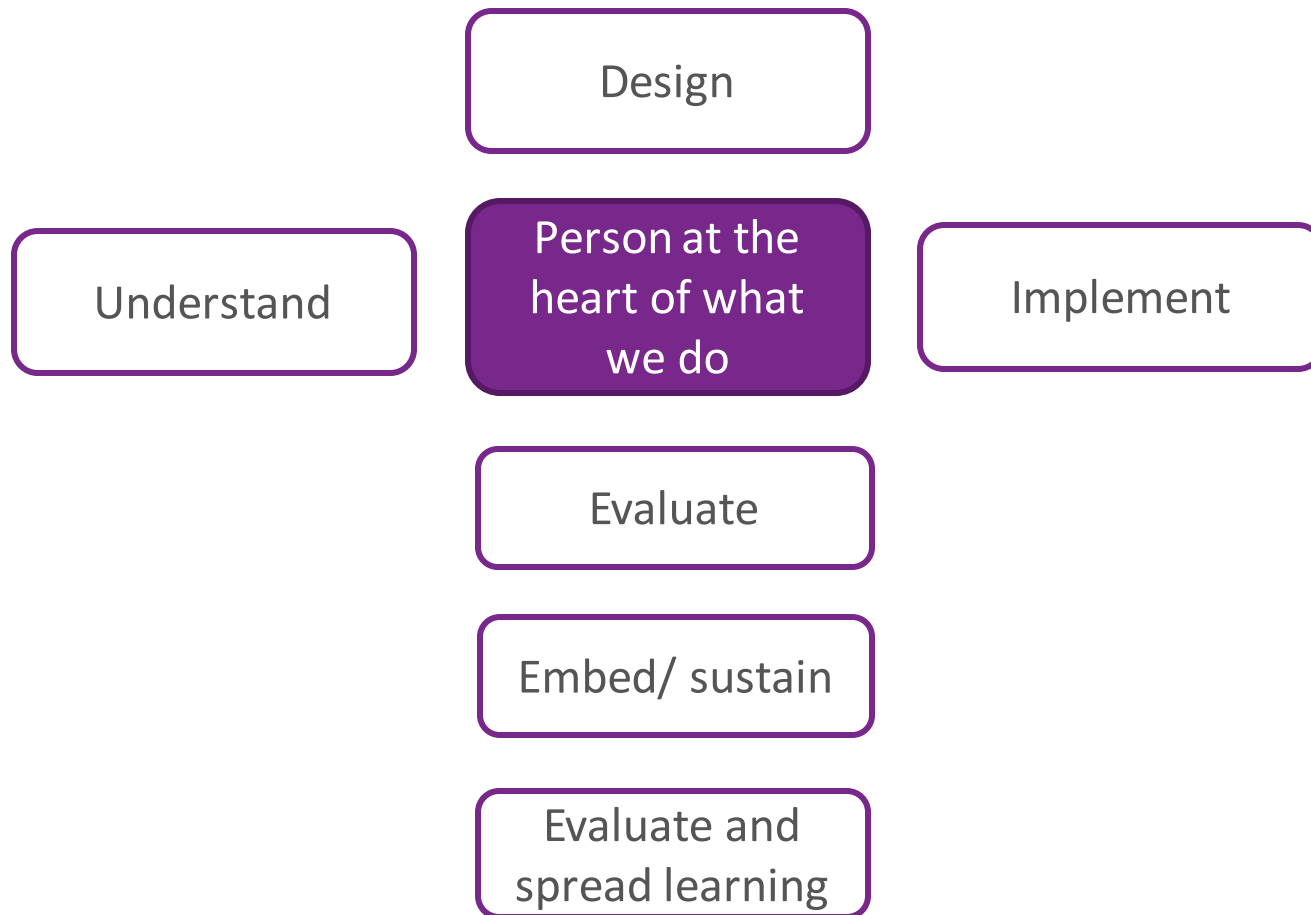
Learning and
Improvement
Networks



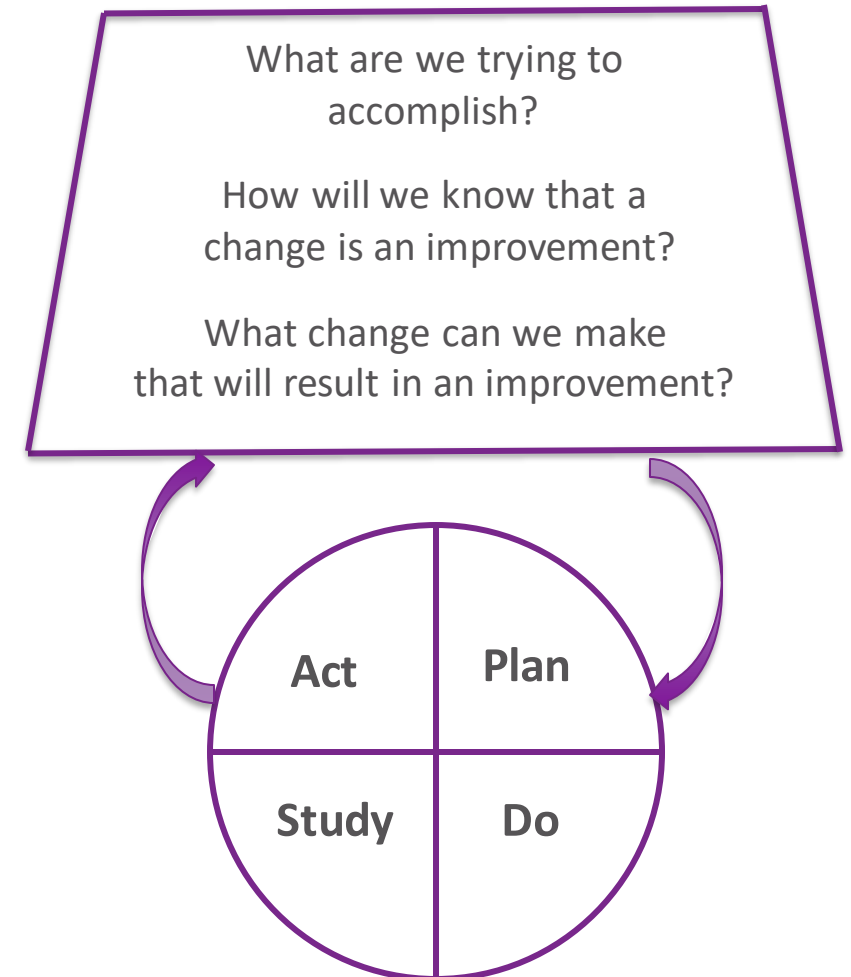
Toolkits and publications

Improvement approaches

Relational approaches/ technical approaches

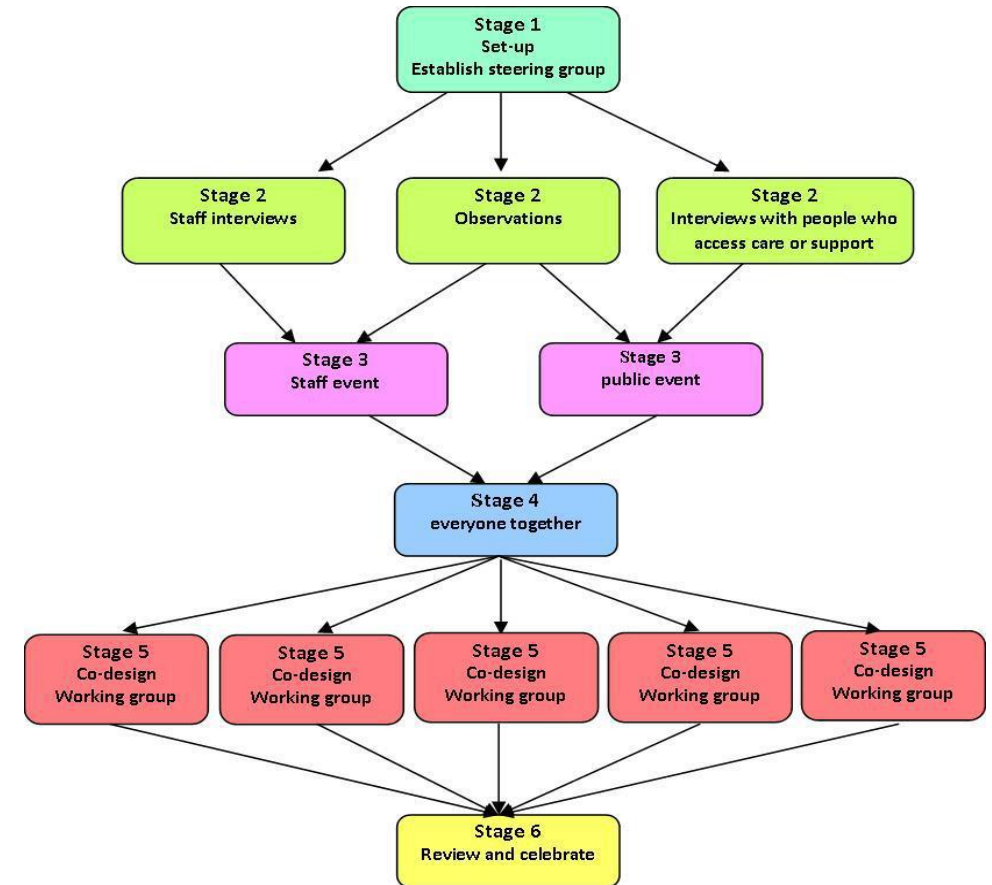


Model for Improvement



Improvement approaches

Appreciative Inquiry 4-D Cycle



Care co-ordination definitions

“ a proactive approach to bringing together care professionals and providers to meet the needs of service users to ensure that they receive integrated, person-focused care across various settings.” (WHO 2018)

“Care coordination was defined as the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care.” (EU Joint Action on Dementia)

Care co-ordination - the evidence

Key Elements

- Continuity with a single named individual responsible for coordinating care and a single point of access through the individual's journey
- Involvement of carers
- Services having adequate knowledge about each one's role and of all available resources in the local area
- Effective exchange of information, which should be relied upon in order to manage all required patient care activities
- Integration and collaboration of care activities in all care settings and sectors.

Priority Practices

- Continuity with a primary care professional
- Collaborative planning of care and shared decision making
- Case management for people with complex needs
- Co-located services or a single point of access
- Transitional or intermediate care
- Comprehensive care along the entire pathway
- Technology to support continuity and care coordination
- Building workforce capacity.

Care coordination benefits



75%

Patients who value seeing their usual primary care provider (5).



High continuity means **13%** fewer hospital admissions (6).



63%

Patients who value seeing someone they know and trust (5).



High continuity means **27%** fewer visits to an emergency department (7).



Coordinated home-based primary care results in **17%** lower medical costs (8).



Hospital at home results in **19%** lower care costs (9).



Over 4 out of 5 People with mental health needs who can be managed through primary care (10).



23 out of 25 studies of medical homes reported reduced use of care (11).

Supporting people with dementia in the community



PDS Leads & Practitioner Networks
3 Test Sites Primary Care
Dementia friendly toolkit
Quality Improvement Framework



Tested 8 Pillars model in 5 areas
Critical Success Factors for
co-ordinated care framework
Care co-ordination commission
(demonstrator site)

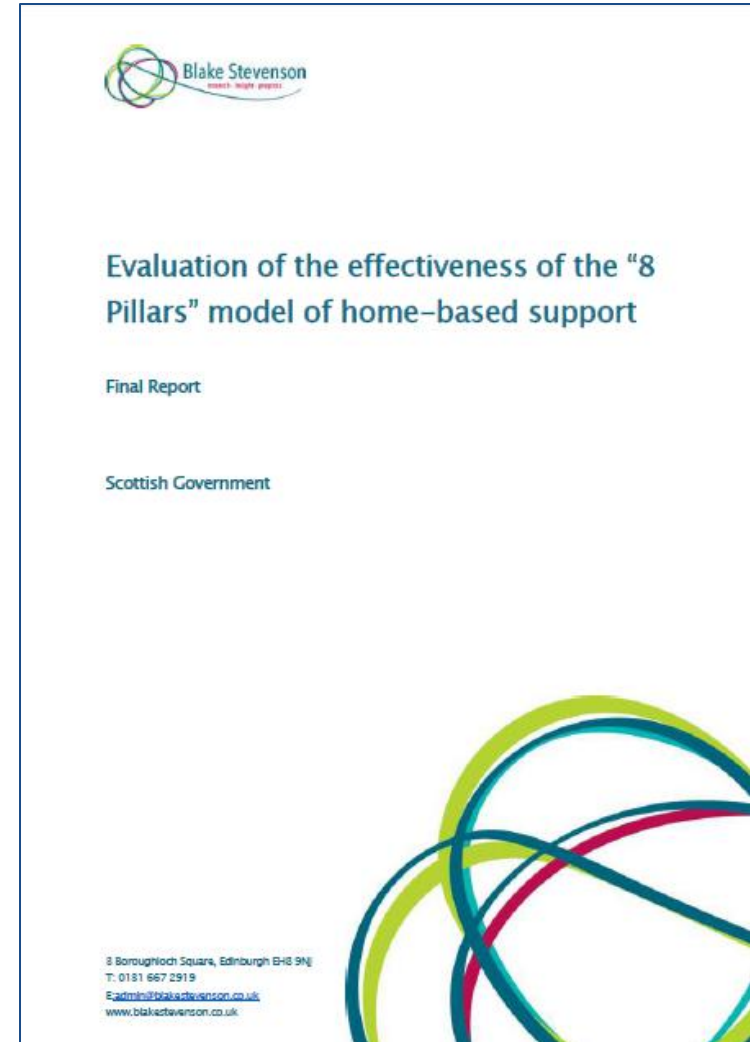


Testing Advanced Model in
Dundee Care Homes

Ref: Alzheimer Scotland models
<https://www.alzscot.org/>

8 pillar testing

- Five areas: Greater Glasgow and Clyde, Highland, Midlothian, Moray and North Lanarkshire
- The test sites began operation in late 2013 and the original two-year duration was extended to June 2016.



Post diagnostic support in primary care

COMMITMENT 2: We will test and independently evaluate the relocation of post-diagnostic dementia services in primary care hubs as part of modernisation of primary care.



By September 2020:

3 test sites

- people with dementia will have access to post diagnostic support from a primary care setting.
- people with dementia and carers will experience high quality post diagnostic support from a primary care setting.
- staff within these sites will have improved knowledge, understanding and confidence in supporting people with dementia and carers.

Identification of critical success factors

Methodology

- Appreciative Inquiry approach in 1 health and social care partnership – Midlothian
- Focus groups/staff interviews
- Quantitative analysis of health and social care data to model care pathways
- Qualitative feedback from users

Findings/Outputs

- ↓A+E, unplanned admissions last 3 months
- ↓unplanned bed day rate, unplanned admission, A+E rate, readmission rates, medical costs
- 12 critical success factors
- Formal report – June 2019
- Framework for spreading the learning

Care Coordination Recommendations

Macro – system level

- Strategic focus on services for people with dementia
- Effective coordination can support more efficient use of resources and therefore it is critical for HSCPs to ensure that this is reflected in the strategic direction.
- Senior HSCP managers have a crucial role as ‘system enablers’ in harnessing the unique contribution of third sector organisations through effective commissioning and coordination on a community-wide basis.

Meso – service level

- Dedicated dementia team.
- Team Culture – QI, inclusion, value and respect, education, administrative support for co-ordination,
- Empowered team.
- Communication – third sector, acute, primary care, people with dementia

Micro – individual level

- People with dementia and carers and team – partnership approach, carer resilience
- Needs based support and Access to support when they need it.
- Cohesiveness of the team.
- Responsiveness

Palliative and end of life care coordination

Vision: By 20:20, Everyone in Scotland who needs palliative care will have access to it

Strategic Framework for Action, Commitment 1: We will provide Health and Social care Partnerships with expertise in testing and implementing improvements to identify those who can benefit from palliative and end of life care and in the co-ordination of their care.

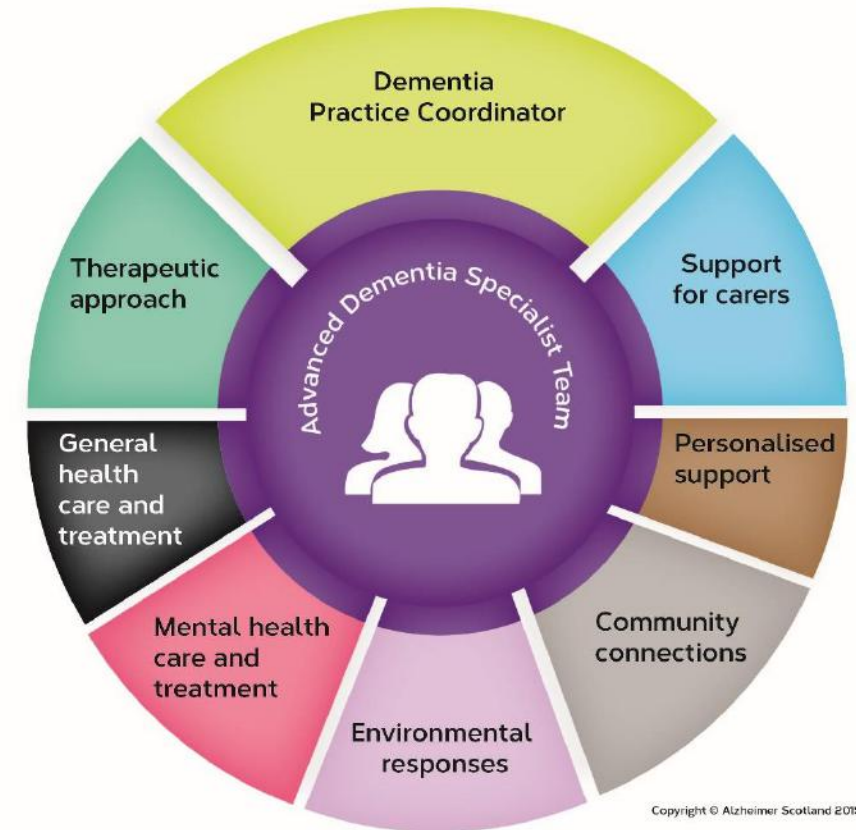
Scotland's National Dementia Strategy 2017-2020, Commitment 5: We will test and evaluate Alzheimer Scotland's Advanced Care Dementia Palliative and End of Life Care Model.

Commitment 6: We will work with stakeholders to identify ways to make improvements in palliative and end of life care for people with dementia.

- 1 in 3 people over 65 may die with dementia (Elliot et al 2014)
- AD/Dementia now account for around 10% of all deaths (NRS 2017)
- The age group most likely to be given a diagnosis 80-84 (SG 2016)
- By 2020 the no. people diagnosed will be 19,473/year (SG 2016)
- 2 in every 5 people with dementia die in hospital (Sleeman et al 2014)
- $\frac{3}{4}$ of people with dementia had at least 1 ED attendance in their last year of life, 44.5% on the last month (Sleeman et al 2017)
- Of those who survive to be discharged, one in five will die or be readmitted within 30 days, and three in five within a year (Reynish et al 2017)
- 26% stay a period in excess of 3 months (McCarthy 1997)
- People with dementia who received palliative care typically did not begin receiving it until 2 weeks before death (Zheng et al 2013)
- People who died in acute care less likely to be referred to palliative care and less likely to be prescribed palliative medicines (Sampson et al 2006)

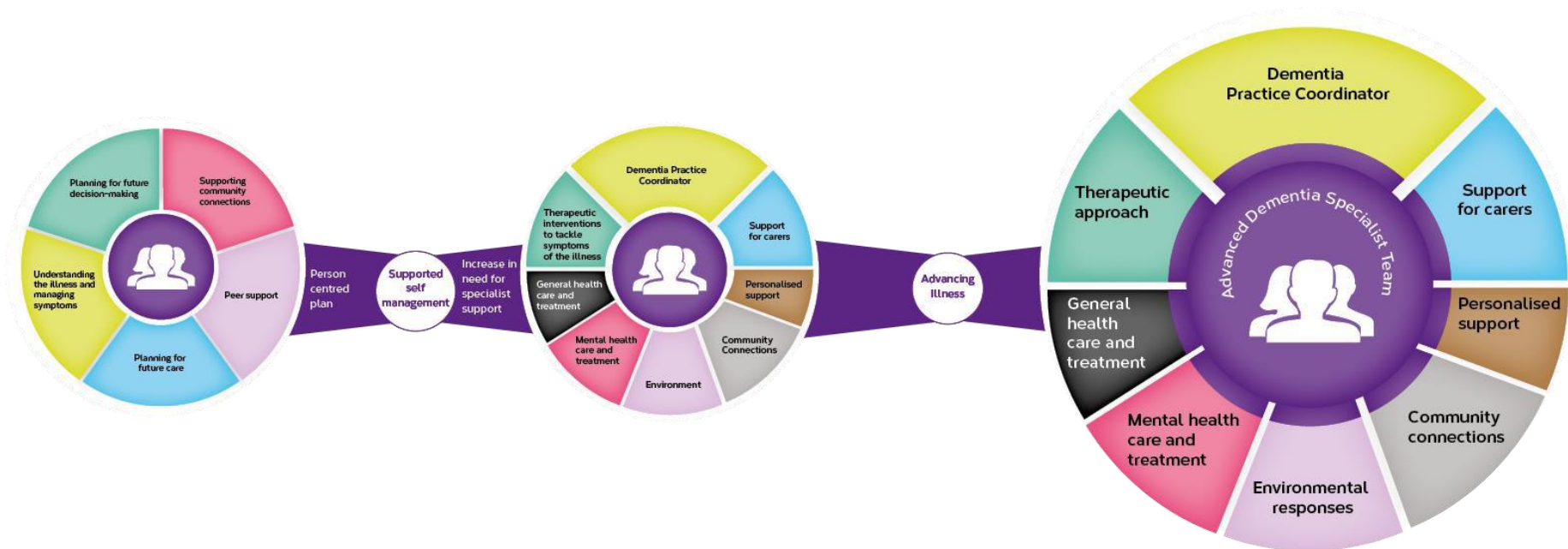
Palliative and end of life care coordination

- Dundee Health and Social Care Partnership
- November 2019
- Testing of palliative and end of life care identification tools – FAST, PPP
- Testing of Alzheimer Scotland Advanced Dementia Practice Model
- Review of care pathway



Whole system redesign

- Implementation of whole system redesign in 1 Health and Social Care Partnership
- “Our shared vision is of a Scotland where people with dementia and those who care for them have access to timely, skilled and well co-ordinated support from diagnosis to end of life which helps achieve the outcomes that matter to them”.



Critical Success Factors



- Involving people with dementia, carers and staff
- Partnership working across sectors and organisations
- Method: using Quality Improvement approaches
- Focus on outcomes that matter
- Staff empowerment and leadership
- Sharing our learning as we go.

Take Home Messages

- Care coordination may mean different things to different people and in different contexts
- There are a number of key elements to successful care coordination
- Our learning is transferable to other conditions and settings

Keep in touch

website: ihub.scot/focus-on-dementia/
email: hcis.focusondementia@nhs.net
twitter: @FocusOnDementia
@lynnflannigan1

Dementia friendly hospitals:

Change the culture, change the care

Danielle Wilde
Group Lead for Dementia,
Royal Free London NHS Foundation Trust

Royal Free London NHS Foundation Trust consists of.....



world class expertise  local care

Royal Free London
NHS Foundation Trust



Dementia in the UK

- >850,000 people with dementia in UK
- At any one time, 6% are a hospital inpatient
- Equivalent to 25% of all NHS beds occupied by a person with dementia
- Within the catchment of the Royal Free London, up to 40%



Dementia in hospitals

People living with dementia who are admitted into hospital;

- Stay in hospital 7x longer
 - More likely to fall
 - More likely to die
 - More likely to be discharged into residential care



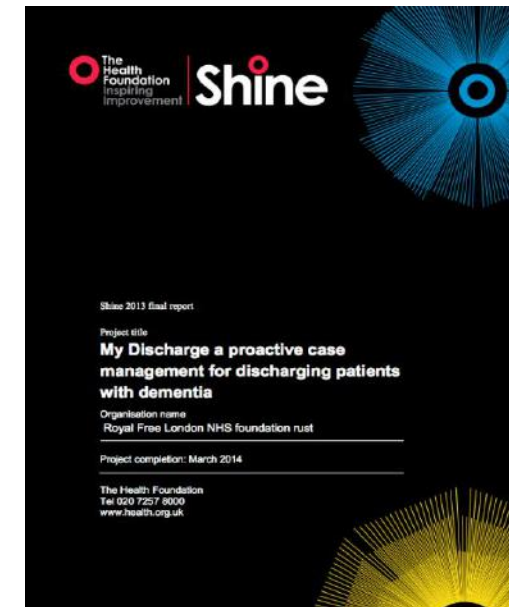
Specialists and Specialities

- RFH awarded Health Foundation bursary to establish dementia specialist OT role
- Ran for 18 months;
- Reduced length of stay by 2.6 bed days
- Reduced readmission by 26%
- 34% patients were for NH but were successfully discharged home

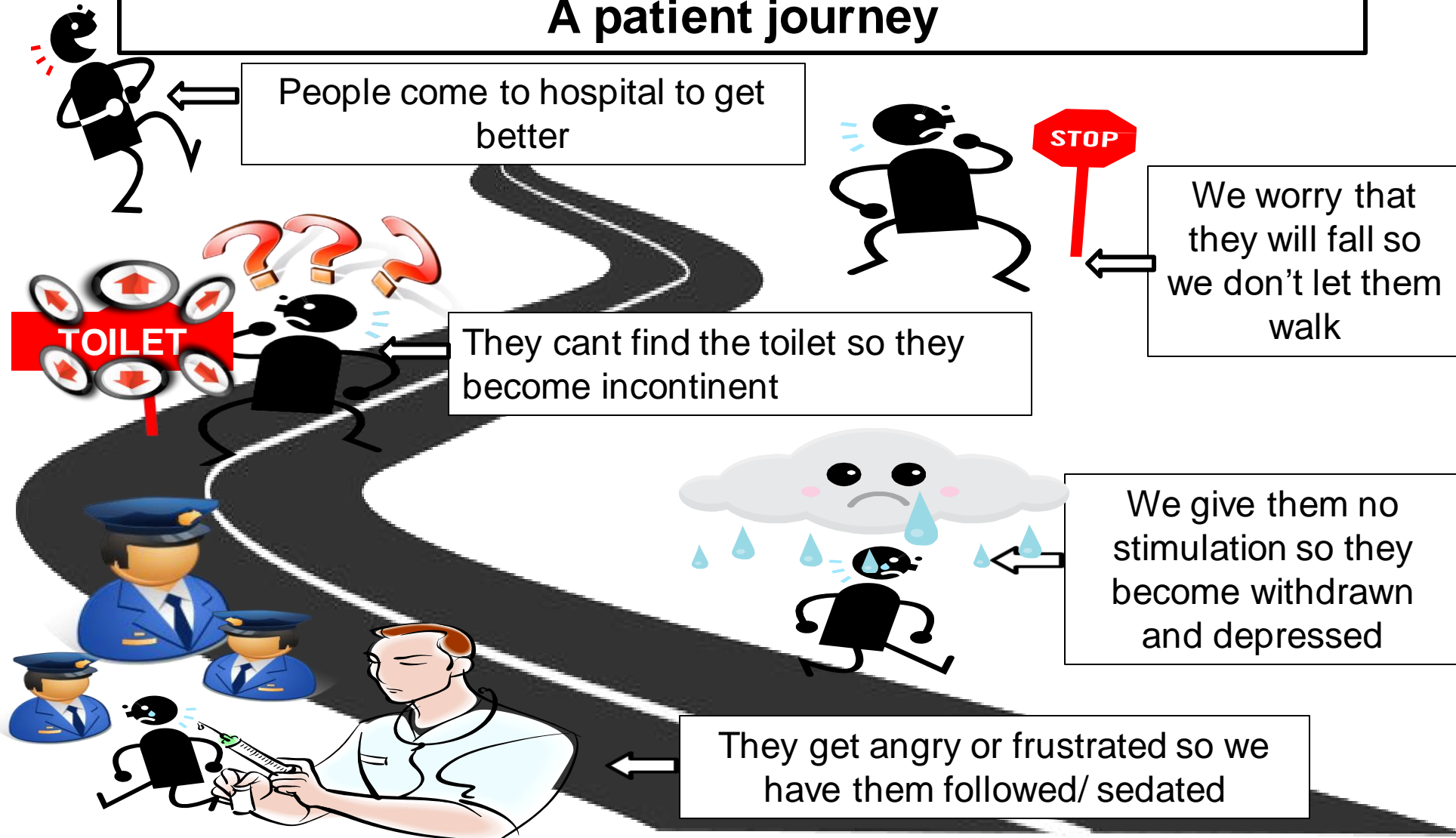


Unintended consequences....

- The specialist role made others feel non specialist
- Inappropriate referrals due to deskilling



Understanding the culture of dementia care: A patient journey



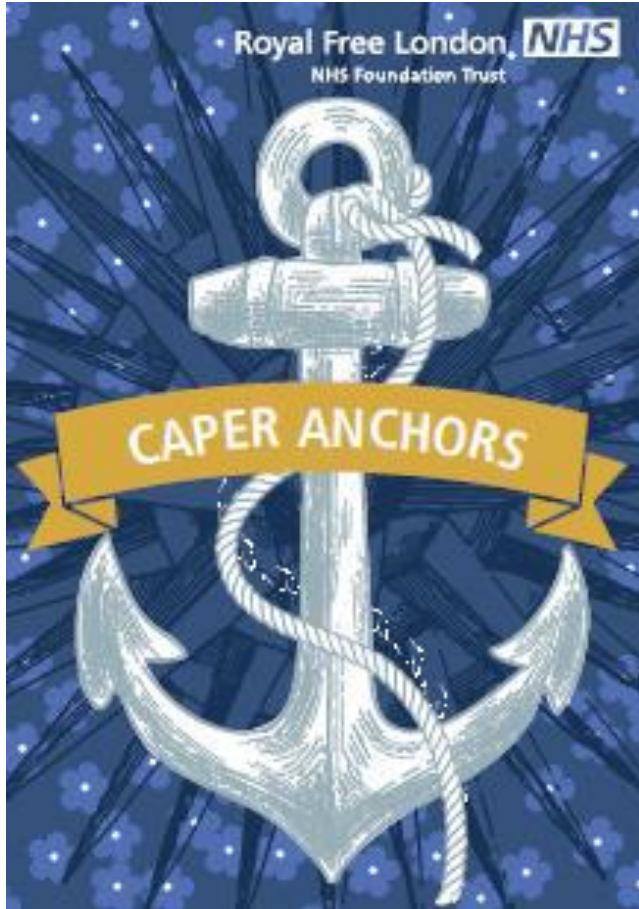
**AND THEN WE SAY THEY HAVE DETERIORATED
"BECAUSE OF THEIR DEMENTIA"!!!**



Culture is the deeper level of basic assumptions and beliefs that are shared by members of an organization, that operate unconsciously and define in a basic 'taken for granted' fashion an organization's view of its self and its environment.

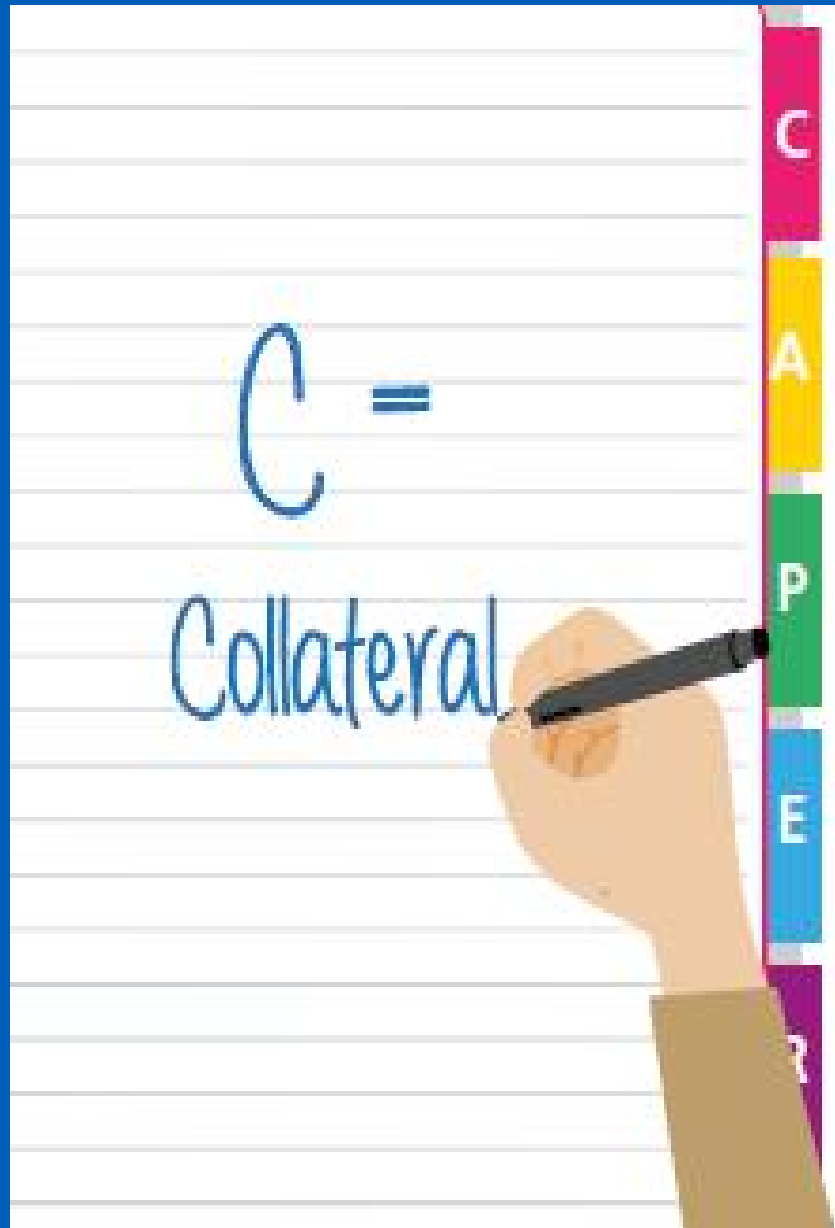
— Edgar Schein —

Developing a roadmap for cultural change



CAPER established an evidence based methodology for treating people with dementia in acute hospitals


- Collateral
- Assessment
- Partnership
- Enablement
- Role-modelling




What matters to you?


Collateral

- 8 things about me
- What matters to you?
- Embedding the tool into daily care
- Humanising care
- Creating opportunities for occupation


Royal Free London 
NHS Foundation Trust



8 important things about ME
(Name.....)

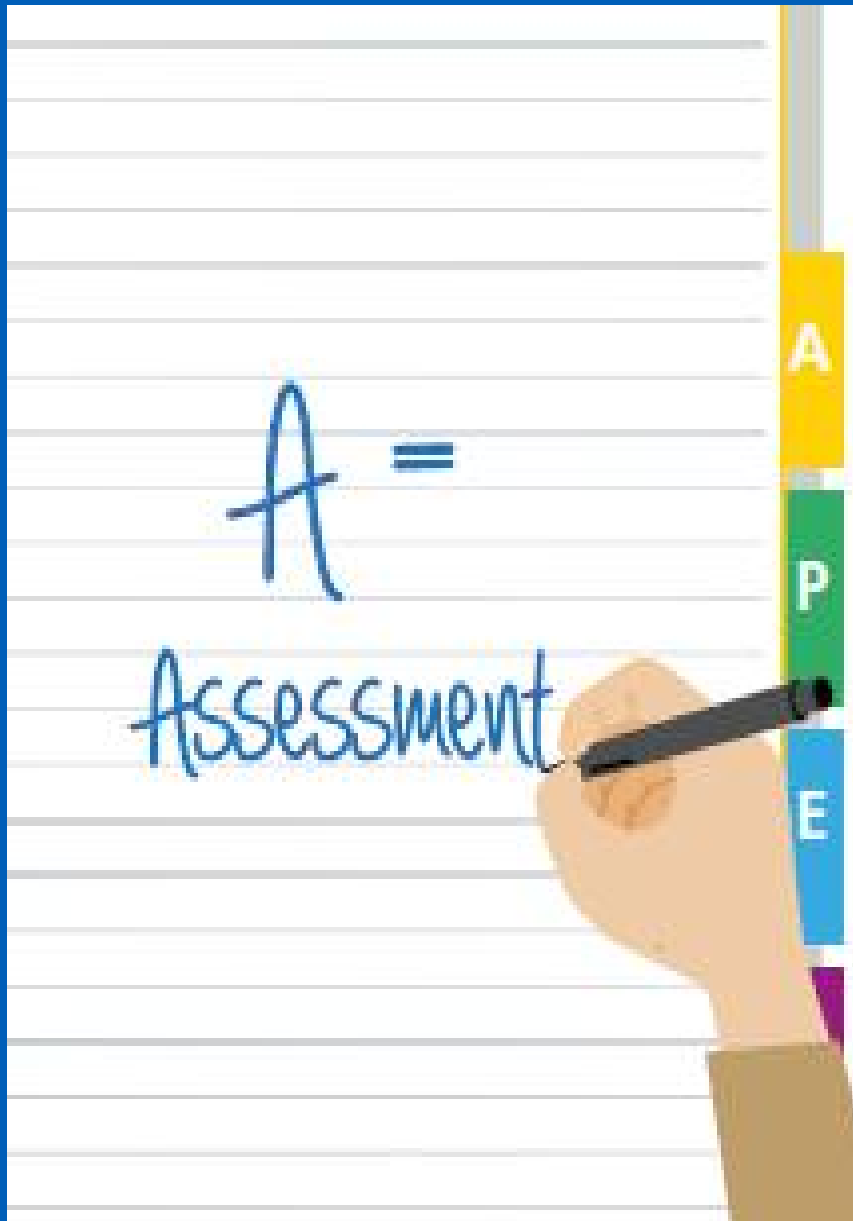


I like to be called	
My job/role was	
When I am in hospital – the person who knows me best and looks after me is	
Please let them come in and support me when I need it	
Likes and dislikes	
My interests/ hobbies:	
What upsets me is:	
Foods/ drinks I like:	Foods/ drinks I don't like:
Signs that I am distressed:	Tips to calm me down:

world class expertise  local care

Learning

- Pharmaceutical management of aggression (for example sedation) decreased by 40%
- Staff confidence in de-escalating early distressed behaviour increased by 85%
- Increased use of patient name in handovers
- Increase in “high-risk” discharges
- Staff 5x more likely to have a social conversation with patients using the “8 Things” as a starting point



Creating a healing environment



world class expertise  local care

Royal Free London
NHS Foundation Trust





world class expertise  local care

Royal Free London
NHS Foundation Trust





world class expertise  local care

Royal Free London
NHS Foundation Trust





world class expertise  local care

Royal Free London
NHS Foundation Trust





world class expertise  local care

Royal Free London
NHS Foundation Trust





world class expertise  local care

Royal Free London
NHS Foundation Trust



Learning

- Absconsions from the ward reduced by 48%
- Improved staff satisfaction and retention
- Reduction of 30% in use of security officers
- Significant increase in patient engagement in care/ therapy
- Increased rates of patients dressed and out of bed during the day



Working with ~~patients~~ people



world class expertise  local care

Royal Free London
NHS Foundation Trust





world class expertise  local care

Royal Free London
NHS Foundation Trust





world class expertise  local care

Royal Free London
NHS Foundation Trust





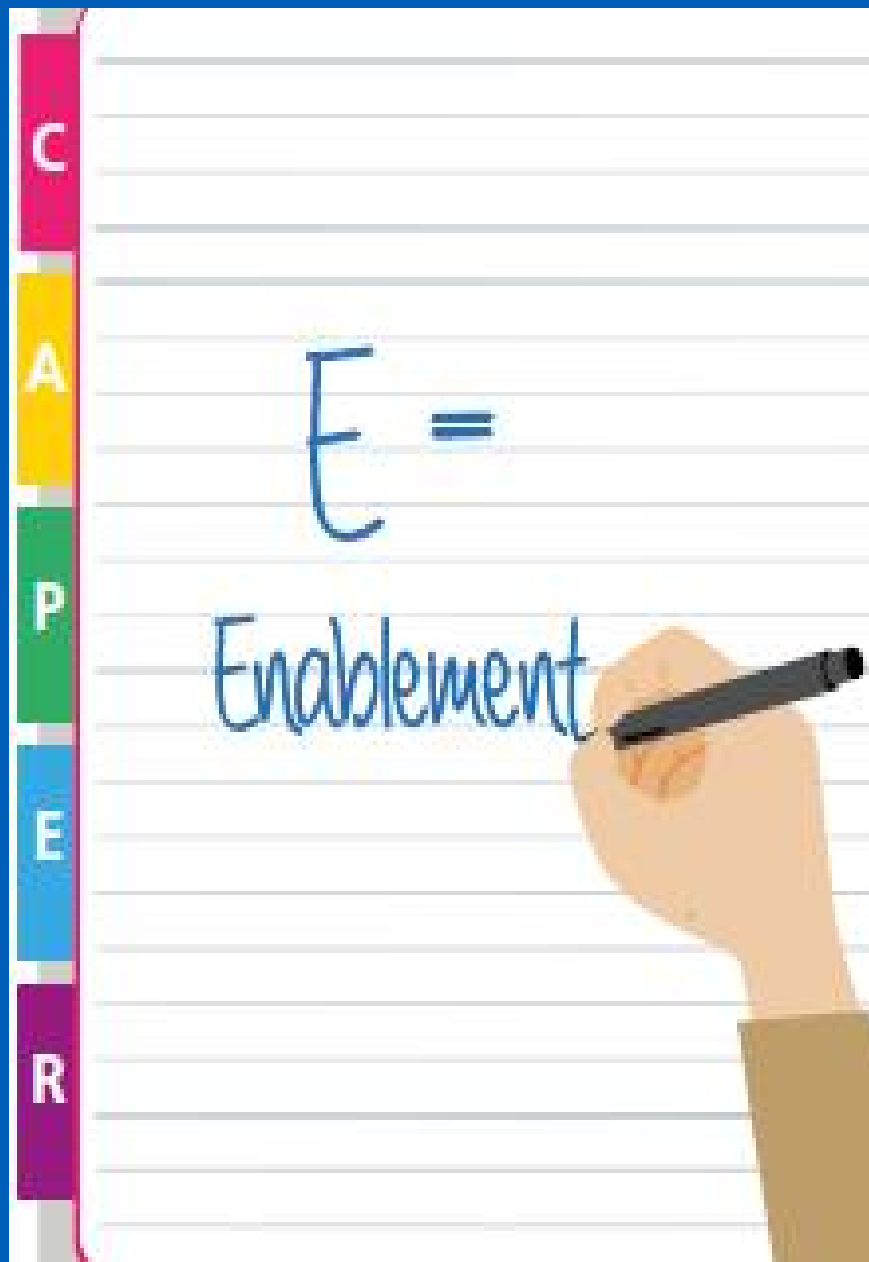
world class expertise  local care

Royal Free London
NHS Foundation Trust



Learning

- Staff given a safe and experimental space to try new techniques and approaches
- Emphasis on improvisational caregiving and the performance of empathy
- Breathing techniques and calming mirror approach being piloted by security officers
- 100% staff felt more confident to manage distressed behaviour and 100% felt improved confidence



The art of dementia care



world class expertise  local care

Royal Free London
NHS Foundation Trust





world class expertise  local care

Royal Free London
NHS Foundation Trust





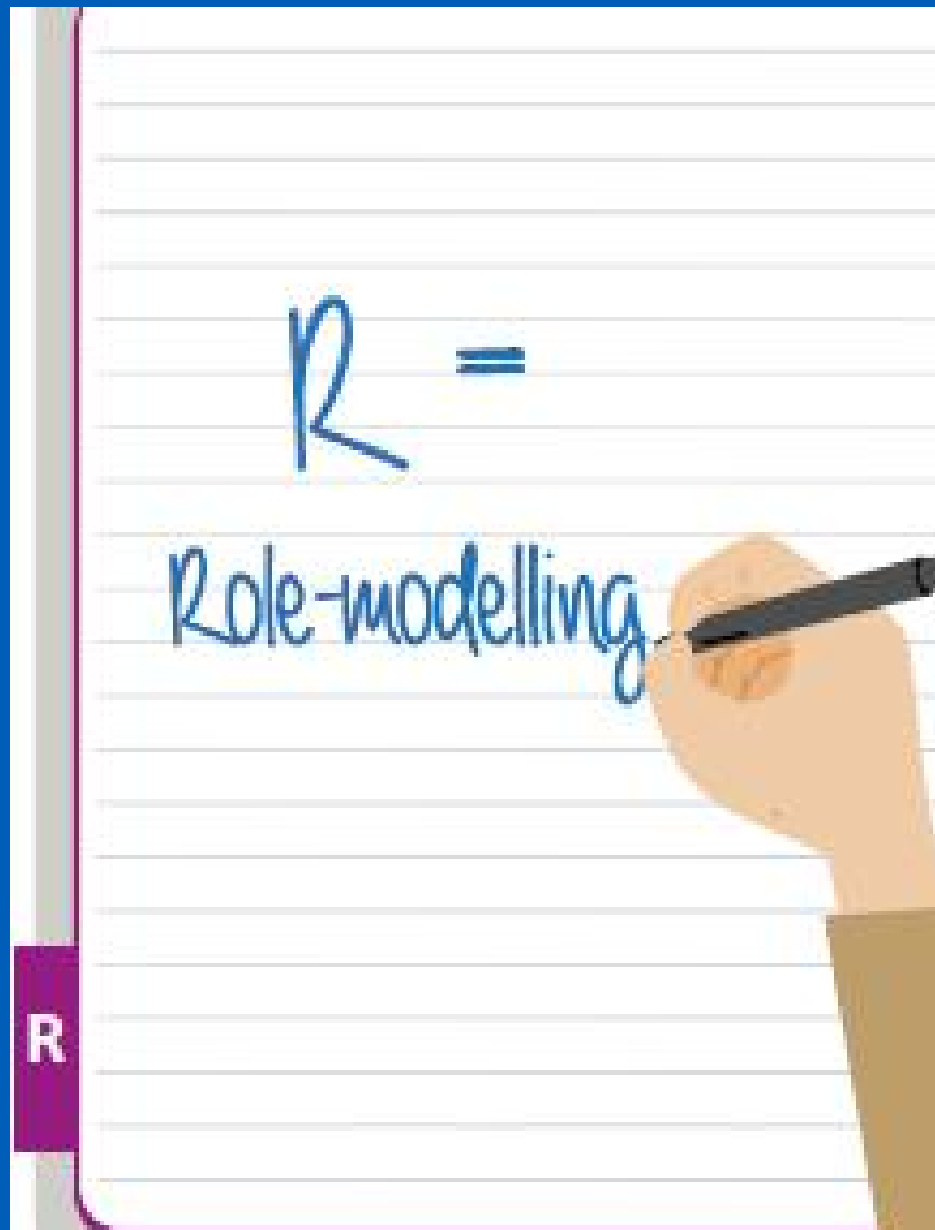
world class expertise  local care

Royal Free London
NHS Foundation Trust



Learning

- Patient care is a performance of tasks. Changing the set changes the script
- Staff have the permission to behave outside of the constraints of clinical character
- Challenging a culture in which bottom wiping is work and conversation is skiving
- Activity groups programmed every day
- Patients eat meals at tables with each other



Joy In Work



“The source of energy at work is not in control, it is in connection to purpose”

Don Berwick



Learn



world class expertise  local care

Royal Free London
NHS Foundation Trust



Learning

- Over 700 colleagues have completed CAPER anchor training
- Increasingly, Anchors are leading improvement efforts in their clinical area linked to their value-based working approach
- You don't have to be the boss to be the leader
- Quality of interactions between staff and patients improved by over 60% (good habits are also contagious)



“The company... has no rights to survive. But value systems and philosophies survive. People take them with them”

Edgar Schein

Change the culture, change the care

Danielle Wilde

Twitter: @DanielleRBWilde

Email: daniellewilde@nhs.net