Healthcare Improvement Scotland

NHS Education for Scotland

care inspectorate

Person-centred approaches to reducing stress and distress for people living with dementia

Toolkit

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Contents

Introduction

This toolkit is a practical resource that can support teams during the planning of improvement activity. It can help teams to understand what part of their service needs to change to enable improvement, identify change ideas for testing and what data to capture to evidence their impact.

This toolkit has been designed to support the aim that:

People living with dementia have improved experience of and access to person-centred approaches to prevent and support stress and distress in hospital and care home settings

This toolkit has been updated from the January 2025 Reducing Stress and Distress Change Package and has been designed to support the implementation of the SIGN 168 guideline: Assessment, diagnosis, care and support for people with dementia and their carers.

How to use this toolkit

The Reducing Stress and Distress Self-evaluation tool has been developed to support teams to evaluate their current practice and identify areas for improvement within their service. It is recommended that this is completed before using this toolkit.

Following completion of the self-evaluation tool, teams can then work through the sections of the toolkit to develop their improvement project. It includes:

- driver diagram
- example change ideas
- supporting evidence, tools and resources, and
- data and measurement guidance.

Sections of the toolkit align with the 6 quality criteria identified in the self-evaluation tool. It is not expected that teams will work simultaneously on all of these criteria.

The change ideas and measures included are not exhaustive. We recommend teams adapt and develop change ideas and measures to fit their context. We also welcome you to share any change ideas you develop by emailing us at his.focusondementia@nhs.scot. We may want to include your ideas in future versions.

Driver diagram: Understanding what needs to change

Before starting a project, it is important for teams to understand what parts of their service need to change to ensure everyone has a shared sense of why improvement is needed and is focused on changes that will impact most beneficially on their system and service.

A driver diagram is a tool that visually presents a team's theory of how an improvement goal will be achieved. It articulates which parts of the system need to change, in which way and includes ideas of how to make this happen. It is used to help plan improvement projects and ensure team engagement.

Primary drivers

Primary drivers are the key components of the system that must change to deliver the aim. They are not listed in order of priority. The reducing stress and distress primary drivers align with the key criteria set out in the self-evaluation tool.

Secondary drivers

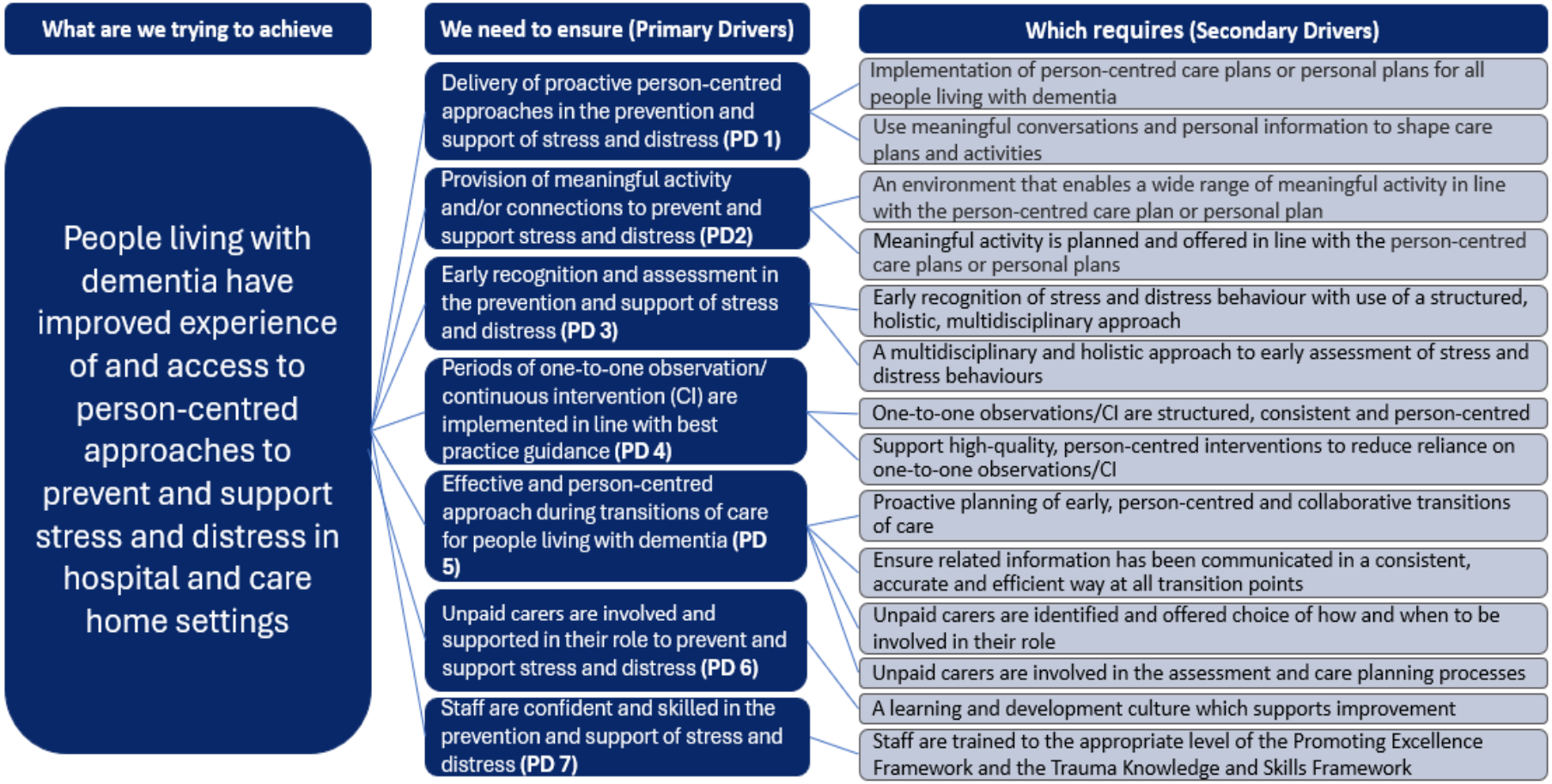
Secondary drivers are the processes that influence primary drivers. Changing the processes outlined in the secondary drivers should lead to achieving the primary drivers.

A driver diagram for delivering person-centred approaches to prevent and support stress and distress for people living with dementia can be found on the next page.

Click for more information about Driver Diagram on NHS Education for Scotland's QI Zone.

Driver diagram

Person-centred approaches to prevent and support stress and distress for people living with dementia in hospital and care home settings



PD 1 – Primary Driver 1 PD 2 – Primary Driver 2 PD 3 – Primary Driver 3 PD 4 – Primary Driver 4 PD 5 – Primary Driver 5 PD 6 – Primary Driver 6 PD7 – Primary Driver 7

**unpaid carers are defined as those who provide care and support to family members, friends, and neighbours*

Change ideas

Once a team has agreed what part of their service they want to change, an aim statement should be developed that outlines what they hope to achieve with their improvement project. More information on developing aim statements can be found on QI Zone.

Teams will then work together to identify change ideas that will help them to achieve their aim. Change ideas are specific practical changes the team can make to alter the processes in their service. These ideas can be tested, and the impact measured to understand and evidence if this change leads to improvement. Teams should select change ideas based on their understanding of their local system. A range of change ideas will need to be tested to make changes across different primary drivers.

In the next section of the toolkit, we provide some examples of change ideas that have previously been tested by hospital and care home teams. Some may be more relevant to healthcare settings while others are more social care focused. The change ideas are grouped by the primary driver that they influence. Teams are encouraged to generate their own change ideas that will help drive change in their local systems. One way of generating ideas is to use the question 'how might we?'. For example, 'how might we engage carers more meaningfully?'.

Over the following pages we will look at each primary driver in turn and provide:

- a short evidence review
- examples of change ideas, and
- useful tools and resources.

We have made this an interactive document, if you click on a primary driver in the driver diagram, it will take you to additional information including tools and resources relating to that driver. At the bottom of each primary driver page, there is a link that will take you back to the driver diagram page.

Primary driver 1: Delivery of proactive person-centred approaches

A person-centred approach tailors support to an individual's unique needs, preferences, life history, and abilities. This proactive approach helps people living with dementia to maintain a sense of identity, purpose and wellbeing and contribute to continuity of care and improved quality of life.

Summary of evidence

People with dementia value involvement in care planning, improving their dignity and autonomy. Tailored care supports identity, continuity and wellbeing. A systematic review by Gwernan-Jones et al (2020) concluded that person-centred care improves experiences for people with dementia, carers and staff. Scottish Government guidance states that shared decision-making strengthens personalised care and reduces inappropriate interventions. There is strong evidence of person-centred practice with better quality of life.

Change ideas

Secondary Driver	Change ideas
Implementation of person-centred care plans or personal plans for all people living with dementia	• Staff document in 'daily logs' the practical implementation of person-centred care throughout the day • Include person-centred care plans or personal plans in admission packs • 'What matters to you' information is visible and accessible to staff for example bedside posters or in shared notes, for example dislikes tea or likes to be known as 'Mr' • Staff are trained in best practice on person-centred care planning such as Mental Welfare Commission Guide and Care Inspectorate Guide • Coloured stickers in care plans to indicate where person-centred care plans or personal plans were used to inform care planning
Meaningful conversations and personal information used to shape care plans and activities	• Use 'What matters to you?' or 'Getting To Know Me' in admission process to capture information about the person living with dementia from families and unpaid carers • Use person-centred approaches like active listening, and communication tools such as Talking mats to support good conversations with people • Capture voices/stories/ feedback from people living with dementia and unpaid carers on what works well and what could be better

	• Create a life story with people and unpaid carers that includes information around their culture, beliefs, language, and identity • Identify '3 things about me' and make this clearly visible in notes so any staff member can quickly identify topics to inform care • Meaningful engagement is written in alternative colour in daily logs to evidence participation

Resources

Resource	What it is and what it's for
Creating a life story for a person with dementia: Dementia UK	A guide and template to support people living with dementia to create a life story to record important information and help others understand relate to them better.
Getting To Know Me: Alzheimer Scotland	An editable form to capture personal details to help staff during a hospital or care home stay.
Guide for providers on personal planning: Care Inspectorate	A guide to support staff to develop personal plans with a focus on personal outcomes for people who experience care.
Guide on person-centred care plans: Mental Welfare Commission	A guide for clinical staff in Scotland on creating care plans for people with mental ill health, dementia or learning disability.
Talking mats: improving communications, improving lives: Talking mats	A visual communication framework which supports people with communication difficulties expressing their feelings and views.
What matters to you?: What matters to you?	A single quality question to engage in meaningful conversations people living with dementia, their families and unpaid carers to help inform decisions about their health and care.

Return to driver diagram

Primary driver 2: Provision of meaningful activity and/or connections

Activities are considered 'meaningful' if they reflect interests, help retain skills, provide a sense of purpose and offer opportunities for interaction and companionship for the person living with dementia.

Summary of evidence

Nonpharmacological interventions reduce agitation through personalised and meaningful engagement. Activities aligned with interests and abilities support cognitive, emotional and physical wellbeing. High-quality care environments prioritise connection, routine and purposeful engagement. Meaningful activity reduces distress, improves mood, strengthens identity and supports positive hospital experiences. (SIGN guidelines)

Change ideas

Secondary Driver	Change ideas
An environment which enables a wide range of meaningful activity in line with the person-centred care plan or personal plan	• Make mealtimes a social experience with staff or unpaid carers, for example personalised food preferences or silicone utensils to reduce noise • Adopt dementia-friendly indoor design principles, for example change layout of dining room, use colour contrast • Adopt dementia-friendly outdoor garden designs (Gardening and dementia) • Use Environmental assessment tools to develop the environment • Create and maintain a meaningful activity trolley with activities that people can use in line with their preferences • Develop discovery box with outdoor materials to stimulate the five senses in line with the person's preferences • Create space within the ward for sensory or reminiscence activity
Meaningful activity is planned and offered in line with the person-centred care plans or personal plans	• Create a meaningful activity planner for individuals based on their preferences • Develop personalised resources to reduce stress, for example discovery boxes, sensory items or 'helping out' to create a sense of purpose • Work with volunteers to provide individualised meaningful activities, for example outdoor activities, music with massage, touch therapy or exercise • Use tools to plan activities, for example Ideas and Activities Toolkit, Cognitive Stimulation Therapy, Arts in Care or Meaningful connections

	• Offer individualised Reminiscence Therapy • Create a Playlist for life with people living with dementia and unpaid carers

Resources

Resource	What it is and what it's for
Arts in care: Care Inspectorate	A programme to support highly skilled artists to work with older people living in care homes.
Environmental assessment tools: University of Worchester	A suite of environmental assessment tools enabling people to create dementia-friendly environments for people living with dementia, their families or unpaid carers. The tools comprise versions for six different setting like care home, health centre or hospital. The tools are available as PDFs of as an App.
Gardening and dementia: Trellis	An article providing helpful tips on garden activities for health and wellbeing, dementia-friendly garden design, planting and garden activities.
Ideas and Activities Toolkit: NHS Dumfries & Galloway	A guide for staff and unpaid carers to engage people in appropriate activities. Purpose is to spend quality time with the person and show that activities do not have to be complicated nor carried out by qualified professionals.
Make a playlist: Playlist for life	A resource to support developing a personalised music playlist that is meaningful to the individual person living with dementia.
Meaningful connections: Care Inspectorate	A resource to promote meaningful, person-centred connections for residents in adult and older people's care homes, supporting wellbeing and human rights. It also helps prepare the sector for the implementation of Anne's Law.
Meaningful connections podcast: Care Inspectorate	A series of podcast where Anne's Law project advisers speak with real-life people about real-life stories, discussing insightful, thought-provoking ideas and tips to stay connected with your loved ones.

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Primary driver 3: Early recognition and assessment

Early recognition and assessment of stress and distress involves a structured process to identify and address the causes of distress in people living with dementia. A holistic assessment should be completed before starting any interventions to prevent worsening symptoms and avoid unnecessary interventions. A multidisciplinary approach includes the person living with dementia and their unpaid carers to fully understand the causes of stress and distress and ensure individuals receive the best possible care and support.

Summary of evidence

Early identification of stress, distress, pain or delirium enables timely intervention. Care planning frameworks emphasise recognising unmet needs early. Early recognition reduces reliance on restrictive or reactive measures. Early assessment is essential for preventing deterioration. Structured approaches for example, Standard Operational/operating Procedures support consistent, proactive assessment.

Change ideas

Secondary driver	Change ideas
Early recognition of stress and distress behaviour with use of a structured, holistic, multidisciplinary approach	• Develop process of identifying people with stress and distress behaviour at daily handover huddle • Document early signs of 'stress,' where person-centred interventions could be supported prior to distress • Use Stress and Distress Symptom Scale (SDSS) to identify stress and distress behaviour • Daily awareness of any change in cognition at daily safety huddle such as 4AT (a rapid clinical test for delirium) or SQiD (Single Question to identify Delirium)
A multidisciplinary and holistic approach to early assessment of stress and distress behaviours	• Use multidisciplinary service rounds and huddles for communication of key information • Develop assessment tool to understand underlying factors related to stress and distress using the CEASE Model • Use of appropriate pain scale or apps for people who cannot self-report pain level, for example Abbey Pain Scale, PainChek • Develop stress and distress care plan for residents identified with stress and distress behaviour

	• Develop a Standard Operating Procedure for multidisciplinary staff around the roles and responsibilities in person-centred assessment and care planning

Resources

Resource	What it is and what it's for
4AT: Rapid clinical test for delirium	A quick clinical assessment tool for delirium and cognitive impairment. '4' refers to 'Alertness, AMT4, Attention, Acute change/fluctuating course' and 'AT' stands for 'Assessment Test'.
Abbey Pain Scale: Right decisions	A tool to measure and evaluate pain in people who may not be able to articulate their discomfort due to conditions like dementia or cognitive impairment. It is useful in late-stage dementia where traditional pain assessment methods may not be applicable.
CEASE Model: NHS Dumfries & Galloway IDEAS Team	A model to consider different aspects of supporting people living with dementia to reduce stress and distress: Comfort, Environment, Activity, Social contact and Engaging.
Finding the why: Care Inspectorate	A series of podcast discuss improving dementia care and reducing inappropriate use of psychoactive medicines in care homes.
PainChek: PainChek	A clinically validated (Nyangu I et al) AI-driven medical device pain assessment for people who cannot verbally communicate their pain, for example people living with dementia or cognitive impairment. It operates on smartphones and tablets where it provides real-time pain scores by analysing facial micro-expressions and user input.
SQiD (Single Question to identify Delirium): McCleary E, Cumming P	A single quality question to help improve early recognition of delirium.

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Primary driver 4: Periods of one-to-one observation/continuous intervention are implemented in line with best practice guidance

One-to-one observation or continuous interventions is a form of restrictive practice and may be required when the person cannot be safely left on their own for short periods of time. It should be implemented in line with best practice guidance. Person-centred therapeutic observation and engagement should focus on addressing underlying risk factors, promoting recovery and supporting individuals to meet their needs. This approach carefully balances the potential distress and long-term impact of high-level observation with the need to reduce immediate risks, such as serious self-harm or violence.

Summary of evidence

Continuous interventions should be therapeutic, person-centred and focused on understanding risk. Observation should minimise restriction by engaging, reassuring and reducing distress. Safety should be balanced with dignity, autonomy and long-term well-being. Observation must be purposeful, skilled and regularly reviewed. Continuous interventions should be framed as a supportive intervention, not solely risk management. Efforts should be made to understand unmet need to prevent the need for continuous interventions.

Change ideas

Secondary Driver	Change ideas
One-to-one observations/continuous interventions are structured, consistent and person-centred	• Develop a one-to-one observations/continuous interventions care plan to include personalised activity • Multidisciplinary team huddles to support and regularly review provision of one-to-one observations/ continuous interventions • Processes to regularly collect data on one-to-one observations/ continuous interventions • Early recognition and treatment of behaviours relating to stress and distress during one-to-one observations/ continuous interventions
Support high-quality, person-centred interventions to reduce reliance on one-to-one observations/continuous interventions	• Staff education and training on principles of one-to-one observations/ continuous interventions • Development of therapeutic spaces in a dementia-friendly environment to provide one-to-one observations/ continuous interventions

	• Engage unpaid carers in information gathering like triggers for stress or distress, interests and activities to support one-to-one observations/ continuous interventions

Resources

Resource	What it is and what it's for
From observation to intervention: Healthcare Improvement Scotland	A guidance document to support and challenge all mental health care practitioners to move away from the traditional practice of enhanced observation and work instead towards a framework of proactive, responsive, personalised care and treatment which puts the patient firmly at its centre.
Use of restraint guide: Mental Welfare Commission	A guidance document to support health and social care professionals on best practice on the consideration and use of restraint in care settings.

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Primary driver 5: Effective and person-centred approach during transitions of care for people living with dementia

Moving between different settings such as home, hospitals and care homes is referred to as a transition of care. Different settings include community, between hospital wards or care home units and may include the mechanism of transfer, for example, ambulance. A person-centred approach during transitions of care should involve person living with dementia, unpaid carers and both the sending and receiving teams and ensure care is tailored to an individual's needs, preferences and abilities.

Summary of evidence

Person-centred planning during transitions reduces distress, supports continuity, improves safety, independence and experience. Identifying unmet needs early prevents decline during transitions. Effective transitions of care should involve the person, family and unpaid carers. Poor transitions increase risk of confusion, decline and avoidable admissions.

Change ideas

Secondary Driver	Change ideas
Proactive planning of early, person-centred and collaborative transitions of care	• Early discharge planning process is in place and includes unpaid carers as outlined in (Equal Partners in Care Carers and Hospital Discharge) • Include people living with dementia in discussing transitions of care process and ensure there is a consistent approach • Include unpaid carers in meetings relating to transitions of care • Complete an individualised Transition of Care plan for each resident with references to Getting To Know Me • Set up weekly phone/video calls between both care settings and unpaid carers for discharge planning • Older Adults Community Mental Health Team provide input in planning for admission
Ensure accurate information is communicated in a consistent and efficient way at all transition points	• Develop a process to ensure dementia related documentation follows the person at transition of care like Getting To Know Me, Stress and Distress care plan summary and Power of Attorney • Create 'Preparing for discharge' resource for unpaid carers • Ensure each resident has a Red Bag that stays with them during transitions of care

	• Develop an electronic process of transferring information digitally between care settings • Develop an agreed transition document for care homes and hospitals to use in same area • Develop discharge protocol for dementia patients leaving hospital for care homes

Resources

Resource	What it is and what it's for
Equal Partners in Care Carers and Hospital Discharge: NHS Education for Scotland	Information and advice on involving carers in hospital discharge planning as outlined in the Carers Scotland Act.
Getting To Know Me: Alzheimer Scotland	An editable form to capture personal details to help staff during a hospital or care home stay.
Hospital admissions and visits: Dementia Services Development Centre	Information on practical guidance on a range of subjects, from preparing for admission, to a hospital stay, to returning home.
Managing transfers of care – A High Impact Change Model: Changes 1-10: Local Government Association	A change model for self-improvement designed to support local system partners to improve health and wellbeing, minimise unnecessary hospital stays and encourage them to consider new interventions.
My discharge: getting discharge right for someone with dementia: Health Foundation	A proactive case-management model for discharging patients living with dementia to give them a safe, dignified, timely and sustainable discharge.
Power of Attorney: Office of the Public Guardian	Guidance on the process of creating and register a Power of Attorney. A Power of Attorney is a written document that lets you plan what you want another person to do for you in the future, should you become incapable of making decisions about your own affairs.

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Primary driver 6: Unpaid carers are involved and supported

Unpaid carers are those who provide care and support to family members, friends, and neighbours. Unpaid carers play a vital role in supporting people living with dementia by providing essential care and emotional support that underpins their wellbeing. Actively involving unpaid carers, recognising and valuing their role, and strengthening the support available to them is essential.

Summary of evidence

Supporting unpaid carers strengthens sustainability of the wider care system. Unpaid carers' involvement improves care quality, continuity and well-being. Unpaid carers want meaningful involvement in care planning and decision-making. Legislation enshrines unpaid carers' rights to support and involvement. Early identification helps unpaid carers understand their role and rights and be recognised as partners in the care of the person they support.

Change ideas

Secondary Driver	Change ideas
Unpaid carers are identified and offered choice of how and when to be involved in their role	• Establish a process to reliably identify unpaid carers and obtain consent to record and share information with staff • Staff complete EPIC modules to develop understanding on unpaid carers (Equal Partners in Care) • Choice of timing and approach for unpaid carers to be involved during admission, shared decision making, care planning and improvement processes • Organise social event that involve unpaid carers, for example garden party or concert that can include structured conversations and focus groups • Include unpaid carer identification checklist in admission packs • Establish a process that provides unpaid carers with a single point of contact • Daily logs are available for unpaid carers to see • Work with people living with dementia and unpaid carers to develop life story book to support meaningful activity

Unpaid carers are involved in the assessment and care planning processes	• Record information from unpaid carer on causes of stress and successful approaches to prevent or reduce stress at home • Create a peer group for unpaid carers to support wellbeing • Develop referral pathway with local organisations who support unpaid carers, such as Meeting Centre, Carers Centre, Alzheimer's Scotland • Feedback to unpaid carers on activities person has engaged with that they could use, for example e-photo frame, music • Signpost unpaid carers to local unpaid carer support and training for example Carers Academy, A local information system for Scotland • Good conversation with unpaid carers to support them to understand and learn more about stress and distress and how to respond

Resources

Resource	What it is and what it's for
A local information system for Scotland: ALISS	An online resource to help people find health and wellbeing services, groups and activities across Scotland.
Brain Health and Dementia Resource Centres: Alzheimer Scotland	Information about local Resource Centres offering friendly, accessible environments for people to access for information, advice or support around dementia.
Carers Academy: University of the West of Scotland	A programme designed to support the needs of family members caring for a relative living with dementia. Running in Angus, Ayr, Lanarkshire and Dumfries.
Carer Centres: Care Information Scotland	Carer Centres operate in local areas to offer practical and emotional support, advice and information.
Equal Partners in Care: NHS Education for Scotland	An online resource to help staff identify, include and support unpaid carers.
Find your local meeting centre: Meeting Centres Scotland	Meeting Centres provide a range of services tailored to the needs and interests of individuals with dementia and support for their families and unpaid carers.
Including family carers as partners in care: Care Inspectorate	A factsheet and link to an information webinar to provide family carers with information on being included as partners in care.
John's campaign Resources: John's campaign	Resources for unpaid carers to advocate for the right to stay with people living with dementia while in hospital.

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Primary driver 7: Staff are confident and skilled

In order to provide effective care to reduce stress and distress in dementia, it is essential to first understand dementia and apply person-centred approaches in practice. Building on this foundation helps staff to respond sensitively and effectively when supporting stress and distress in people living with dementia, leading to better quality of life outcomes

Summary of evidence

Skilled staff create safer and more therapeutic environments. Skilled and confident staff deliver more compassionate, person-centred care. Staff capability directly influences outcomes and distress reduction. Trauma-informed and dementia-skilled frameworks help staff understand behaviour as communication. Knowledge-into-action approaches help embed evidence-based practice.

Change ideas

Secondary Driver	Change ideas
A learning and development culture which supports improvement	• Involve a wider range of staff in care planning such as Support Workers and Allied Health Professionals • Support and encourage staff's continual learning and development through wider dementia networks like Dementia Ambassador Group • Consistent approach to staff development via regular check-ins, personal development reviews, appraisals, experience survey, staff survey or Values Based Reflective Practice • Share learning about improvement work and learning / development opportunities in noticeboard or newsletters • Organise drop-in sessions for staff to learn about non-clinical approaches to care and support • Identify a 'go to' person who can support staff and advise in day-to-day care in response to stress and distress • Reflective practice time for staff to 'debrief' on what has gone well

Staff are trained to the appropriate level of the Promoting Excellence Framework and the Trauma Knowledge and Skills Framework	• A planned approach to staff dementia training and development is in place, with protected time for learning to allow staff to demonstrate their knowledge and skills in practice NHS Education for Scotland for Promoting Excellence Framework relevant to their role or Scottish Social Service Scotland Dementia skilled improving practice: learning resource • Opportunity is provided for staff to actively share their learning with peers to strengthen the teams knowledge and skills • Provide protected time for staff training and education • Create staff training records aligned to promoting excellence • Deliver training on assessing changes in cognition and delirium for example 4AT • Develop a weekly multidisciplinary group to share learning on supporting stress and distress

Resources

Resource	What it is and what it's for
NHS Education for Scotland: Once for Scotland Learning Site	This dementia learning site offers a comprehensive suite of learning resources, including e-Learning aligned to the Promoting Excellence frameworks across a range of topics, one of which is Trauma Informed and Responsive Practice in Dementia Care.
Care Inspectorate: Dementia Resources	Website providing information, resources and guidance to help support people living with dementia.
Care Inspectorate: Practical Dementia Resource	The resource tool is designed by and for care staff and people with lived experience of dementia. The tool contains short, real-life stories and tools that facilitated a non-pharmacological approach to improved dementia care.
Scottish Social Services Council: Dementia skilled improving practice: learning resource	A learning resource to support development of the knowledge and skills set out at the Dementia Skilled Practice Level of Promoting Excellence for people working in social service, studying or delivering associated qualifications and awards and working in health and other settings.
NHS Education for Scotland: Responding to distress in dementia: A staff supported guide for carers	This online resource provides helpful information to support unpaid carers to understand and learn more about stress and distress and how to respond.
NHS Education for Scotland: Values Based Reflective Practice (VBRP)	Online learning to learn about VBRP which is a model developed by NHS Scotland to help staff deliver the care they came into the service to provide. It does this by promoting regular inter-disciplinary group reflection. This is to enable practitioners to understand and recognise their personal and professional value and to support them in delivering safe, effective and person-centred care.

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Testing your change idea

Once you have identified your change idea, you will move into the next phase of testing your change idea. Plan, Do, Study, Act (PDSA) cycle is a quality improvement tool that can be used to test an idea and assess its impact. It allows us to test changes on a small scale, to learn from the results, make adjustments and then to test changes under different conditions.

What is it?

Plan
- Have a clear objective
- Make some predictions about what will happen
- Questions and predictions
- Plan to carry out: Who? When? How? Where?

Do
- Carry out plan
- Document problems
- Capture feedback/ observations

Act
- Make decisions about what to do next
- Adopt, adapt, abandon
- Ready to implement?

Study
- Analyse data
- Compare to predictions
- Summarise
- Use knowledge to update your theory about this change

An example of a completed PDSA cycle can be found in Appendix 1.

Click for more information about PDSA on NHS Education for Scotland's QI Zone including the blank template.

Measuring impact

Information gathering or data collection is important for evaluating your change idea, understanding the impact of change to make informed decisions about next steps. There are different types of data and a range of measures to choose from to evidence the impact of your change ideas.

Qualitative data is data that involves words. Stories and feedback give rich qualitative data. They are a very powerful way of finding out where opportunities for improvement lie, and of understanding and describing the impact of improvements.

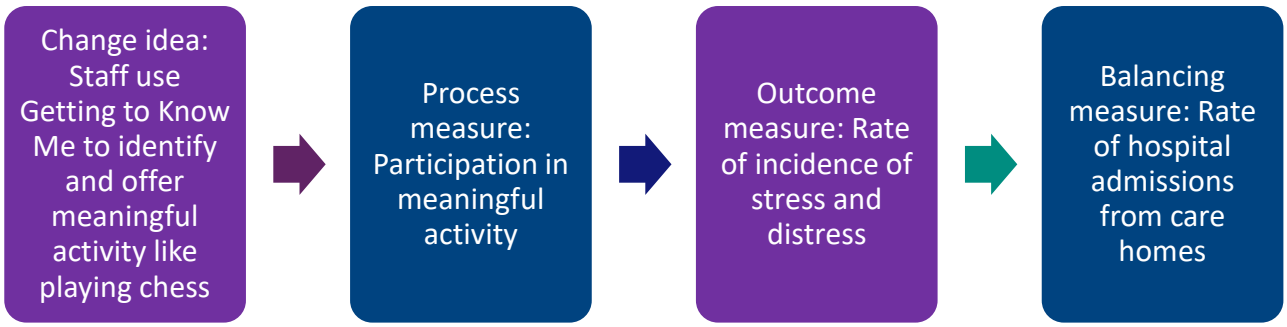
Quantitative data is data expressed in numbers. It can be gathered through the use of closed questions, such as 'yes' or 'no' responses, multiple-choice options or a rating system. It can generally be expressed in a graph or chart and is simple and quick to analyse. NHS Education for Scotland's QI Zone provides more information about Introduction to Measurement, Measurement Journey and Measurement Plans.

When deciding what data you want to capture, think about what you already measure and make sure you are only collecting what is necessary. For easy ways to help support data collection in busy care home and hospital environments, please see Appendix 2.

Outcome measures are used to understand if changes are resulting in improvements towards the aim.

Process measures are used to reflect the way your systems and processes work that lead to the outcome measures, are context specific and depend on the change ideas being tested and implemented.

Balancing measures are used to check for possible consequences elsewhere in the system (unintended consequences). Balancing measures will depend on the focus of your improvements and some examples below may work better as process measures.



The following measures are examples for teams to consider when implementing improvement activity to reduce stress and distress. This is not an exhaustive list and teams should develop their own measures based on the change ideas they are testing locally. Some measures will need adjusted for different settings and to align with different data collection systems.

Outcome measures

Concept	What/how to measure
Experience of people living with dementia and their unpaid carers (OUT1)	Feedback on the care experience of people living with dementia and their unpaid carers. There are numerous ways to gather feedback. Below are a few resources that you may want to use: • NHS Education for Scotland: Dementia standards: Supporting change tool • Care Inspectorate: EQ - people experiencing care - final.docx and EQ - Relatives - final.docx and • Healthcare Improvement Scotland: Participation Toolkit, specifically Engaging to understand and Engaging to inform change sections.
Incidents of stress and distress (OUT2)	Use of safety cross (Appendix 3) to record incidences of stress and distress, Or Rate of incidents of stress and distress for people living with dementia in the hospital ward or care home. In hospital settings, this may be recorded as incidents of violence and aggression per month. **Numerator:** Total number of incidents of stress and distress within the last calendar month. **Denominator:** Total number of occupied bed days for the month **Rate calculation:** (numerator/denominator) * 100^. *^numerator/denominator divide by 100* Use of existing tools such as Excellence in Care: Occupied bed days.
Falls (OUT3)	Use of safety cross (Appendix 3) to record number of falls Or Rate of falls per 1000 occupied bed days of people living with dementia in the hospital ward or care home per month. **Numerator:** The total number of falls within the last calendar month. **Denominator:** Total number of occupied bed days for the month. **Rate calculation:** (numerator/denominator) * 1000. Use of existing tools such as Excellence in Care: Fall rates.

Process measures

Concept	What/how to measure
Person-centred information influences the development and delivery of person-centred care plans/ personal plans (PRO1) Related to PD 1,2	Percentage of people living with dementia where there is evidence that person-centred information like Getting to Know Me or similar document has influenced the development and delivery of their person-centred care or personal plan per week. **Numerator:** Number of people living with dementia with a person-centred care plan or personal plan that documents individual preferences using Getting To Know Me and how these have been met per week. **Denominator:** Number of care or personal plans reviewed using agreed sample number per week. **Percentage calculation:** (numerator/denominator) * 100.
Participation in meaningful activity (PRO2) Related to PD 1,2	Percentage of people living with dementia that have participated in personalised and meaningful activity per week. **Numerator**: The number of people living with dementia of the records sampled who have engaged with meaningful* activities documented within their care plan daily (previous 3 consecutive days) per week. **Denominator**: Number of care or personal plans reviewed using agreed sample number per week. **Percentage calculation:** (numerator/denominator) * 100. **Activity will be considered 'meaningful' if it has been identified as important to that person through the person-centred care planning process.*
When-required (PRN) psychoactive medicine administered (PRO3) Related to PD 2	Use of safety cross template (Appendix 3) to record when PRN psychoactive medication is administered. or Rate of PRN psychoactive medicine administered to people living with dementia per week. Use of local existing tools if available such as care home Medicines Administration Records (MAR) charts. **Numerato**r: The number of PRN psychoactive medication administered the last calendar week. **Denominator**: Total number of occupied bed days for the week. **Rate calculation:** (numerator/denominator) * 100.
Appropriate assessment or screening tool completed (PRO4) Related to PD 3	Percentage of people living with dementia who have an appropriate assessment or screening tool completed within 48 hours of admission per week. **Numerator:** Number of people living with dementia within the service who have an appropriate assessment or screening tool completed within 48 hours of admission per week. **Denominator:** Number of care or personal plans reviewed using agreed sample number per week. **Percentage calculation:** (numerator/denominator) * 100.

Hours people living with dementia receive one-to-one observations/ continuous intervention (PRO5) Related to PD 4	Rate of total number of hours people living with dementia receive one-to-one observations/continuous intervention per week. **Numerator:** Number of hours of one-to-one observations for people living with dementia within the last calendar week. **Denominator:** Total number of occupied bed days for the week. **Rate calculation:** (numerator/denominator) * 100.
Unpaid carers are identified (PRO6) Related to PD 6	Percentage of people living with dementia where the outcome of a conversation to identify unpaid carer/s is recorded per week. **Numerator:** Number of people living with dementia where the outcome of a conversation to identify an unpaid carer is recorded per week. **Denominator:** Number of people living with dementia admitted to the hospital ward or care home using agreed sample number per week. **Percentage calculation:** (numerator/denominator) * 100.
Unpaid carers have had discussions with staff to identify their support needs (PRO7) Related to PD 6	Percentage of unpaid carers who have had a discussion about their support needs and the outcome of the discussion recorded per week. **Numerator:** Number of unpaid carer records with discussion recorded (including where no support is needed) per week. **Denominator:** Number of identified unpaid carers using agreed sample number per week. Percentage calculation: (numerator/denominator) * 100.
Staff have appropriate level of knowledge and skills (PRO8) Related to PD 7	Percentage of staff who have completed training to the relevant level of the Promoting Excellence Framework (PEF) as per training needs analysis in their area of practice per month. **Numerator:** Number of staff who have completed the relevant level* of PEF training and have evidence of implementing skills into practice per month. **Denominator:** Total number of staff in the ward or care home per month. **Percentage Calculation:** (numerator/denominator) * 100. **Relevant level (Informed, skilled, enhanced or expertise) will be based on the descriptions in the framework and each staff's role and level of contact with people living with dementia.*

Balancing measures

Concept	What/how to measure
Spend on staff for one-to-one observations (BAL1)	Percentage spend on staff for one-to-one observations per month. **Numerator:** Total financial spend on additional staffing to cover one-to-one observations per month. **Denominator:** Total financial spend for core staff in hospital ward or care home per month. **Percentage calculation:** (numerator/denominator) * 100.

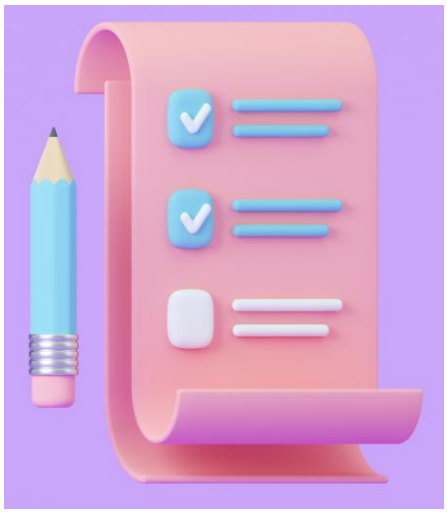
	Use of existing tools if appropriate such as: • Excellence in Care: Supplementary staffing use – overtime and excess • Excellence in Care: Supplementary staffing use – bank and agency
Length of stay in hospital (BAL2)	Average length of hospital stay for people living with dementia from admission to discharge in hospital per month. **Numerator:** Total length of stay in days at discharge for all patients living with dementia per month. **Denominator:** Total number of patients living with dementia discharged from the hospital ward per month. **Average calculation:** (numerator/denominator). For hospitals only.
Delayed discharges in hospital (BAL3)	Rate of patients living with dementia with delayed discharge* in hospital ward per month. **Numerator:** Number of delayed discharge bed days in hospital ward within the last calendar month. **Denominator:** Total number of occupied bed days in hospital ward per month. Rate calculation: (numerator/denominator) * 100. **patients who are still delayed and those who were delayed but now have been discharged.* For hospitals only
Admissions to hospital from care homes (BAL4)	Use of safety cross template (Appendix 3) to record when there is an admission to hospital from care home. or Rate of admissions to hospitals from care homes per month. **Numerator:** Number of admissions to acute or community hospital from care home per month. **Denominator:** Total number of occupied bed days in the care home per month. Rate calculation: (numerator/denominator) * 100. For care homes only.
Staff sickness or absence rates (BAL5)	Percentage of hours lost to staff sickness or absence per month. **Numerator:** Number of hours of sickness absence per month. **Denominator:** Total number of hours per hospital ward or care home for all staff per month. **Percentage calculation:** (numerator/denominator) * 100.
Staff experience and wellbeing	To determine staff experience and wellbeing in the service. Use of existing local staff experience tools such as: SPSP Safety Climate Resource: Staff Questionnaire

Appendix 1: Example of a completed PDSA cycle

PDSA unpaid carers identified and involved in care home

Aim (overall goal for this project)			
80% of residents living with dementia or have cognitive impairment will have families/unpaid carers identified early and involved in the assessment and care planning processes in Care Home by December 2025.			
Change idea			
Residents living with dementia or have cognitive impairment will have consistently identified and record details of Next of Kin (NOK).			
PDSA objective: Describe the objective for this PDSA cycle	**Cycle No: 1**	**What questions do you want answered for this test of change?**	
Staff will be able to identify and record NOK details.		Will there be challenges to identify and recording NOK?	
Plan			
Predict what will happen when the test is carried out.		**Measures to determine if prediction succeeds**	
1. Staff is able to identify and record NOK details for current residents 2. Staff is able to identify and record NOK details for residents within 48 hours of admission		1. Number of residents with NOK details completed 2. Time of NOK details completed for residents on admission	
List the tasks needed to set up this test of change.		**Person responsible**	**When to be done**	**Where to be done**
1. Identify staff to do baseline audit 2. Identify staff to change template of daily Handover sheet		Manager Manager	17 Oct 25 17 Oct 25	Care Home Care Home
Do	**Describe what happened when you ran the test.**		
Deputy Manager undertaken 1 baseline data collection on 08 Oct 25 on identified residents living with dementia or have cognitive impairment. She collected data for 11 residents on completion of Getting To Know Me (GTKM) and Person-Centred Care Plans (PCCP). Care Home Worker looked at NOK details for identified residents and updated them whenever possible. Deputy Manager added 1 column in daily Handover sheet for staff to confirm that they have up to date NOK details and that the information has been saved on resident records.			
Study	**Describe the measured results and how they compared to the predictions.**		
Handover sheet tested and each staff was to update the info in the new column to confirm NOK details have been completed and updated on resident records. Deputy Manager reported that there was variation in how staff complete the new column. Some staff just put a tick in the column while some staff put the date NOK details was confirmed. She would like to ensure that the information on when the NOK details were asked to ensure that the staff know to update the details bimonthly for residents. Staff initially reported that they felt having to complete an additional column in the Handover sheet felt like extra work but after testing it, they reported that it didn't take long and staff saw the benefit on ensuring NOK details are up to date. The staff also reported that having up to date NOK details so that they can be contacted at the right time during the residents' stay and not just at admission. Manager identified Care Home Worker as an initial staff to collect data as it is a good opportunity to mentor newly qualified staff in both clinical and data collection aspects that they are able to identify if the patient is appropriate for the data collection and identify if docs are completed. He will then mentor more Care Home Workers in collecting data as an opportunity to increase awareness and ownership of this project's aim. This will also increase the pool of staff being able to be involved in this project.			
Act	**Describe what modifications in the plan will be made for the next cycle from what you learned.**		
Handover sheet – change column text to asking staff to put in the date NOK details was updated and leave blank if not done. This will highlight to staff at Handover whether they need to update NOK details when it's due. Manager and Deputy Manager will mentor Care Home Worker on collecting baseline data for this week. They will subsequently mentor other newly qualified staff to collect baseline data and identify residents who have to complete GTKM documents. They will also take the opportunity to inform staff about the rationale of the aim and change idea of this project.			

Appendix 2: Practical measurement tips



Paper and pen

- We can use this to tally number of instances of an event, or behaviour, for example of stress and distress, falls, administration of PRN psychoactive medication or admissions to hospitals from care homes.
- Quick tallying events creates immediate organised dataset.
- Feeds directly into process measures (easy to see if a change is an improvement).
- The safety cross is a great example of using paper and pen to record the number of instances of falls/ stress and distress incidences. The safety cross is a visual tool designed to help teams gather information quickly and provide an easy, 'at-a-glance' update for your care home or hospital ward. Guidance on how to use the safety cross, an example on how to complete it as well as a blank safety cross for you to print and use is available in Appendix 3.

Jars and beads

- We can use beads for counting the frequency of an incident.
- Each time there is an instance of x, put a bead in the jar.
- Count the number of beans at the end of each reporting period (for example each week or month).
- We can gather baseline information and see if any changes you've introduced are an improvement.
- Easy to repeat – can be stored at clinical station so it becomes part of the routine after each care home/ward round.

Whiteboard and magnets

- We can use this to visually represent the number of instances of x.
- Each time x happens, stick a magnet on the board.
- Count the number of magnets at the end of each reporting period.
- Easy to repeat after introducing any changes.

Appendix 3: Safety Cross and how to complete it

All participating teams are asked to use the safety cross template to collect information on:

- Number of incidences of stress and distress
- Number of falls
- Number of times when necessary (PRN) psychoactive medication is administered, and
- Number of admissions to hospital from care home (only care home teams to collect).

A safety cross is a visual tool designed to help teams gather information quickly and enable easy, 'at a glance' monitoring of your project. The safety cross is not intended to replace the reporting systems that you may already have in place, rather the safety cross should complement them by encouraging early detection.

How to complete the safety cross

- Each safety cross represents one calendar month. Within each cross there are 31 boxes, as each box represents a single day.
- Agree the most appropriate time for completion and who will do this e.g. morning safety huddle. One box should be completed each day.
- Each type of occurrence will be recorded using a different colour. To the left of the Safety Cross is a key that identifies what colours to use.
- For each day:
  - colour the box to reflect the type/s of incidence that have occurred
  - use the appropriate colour to write the number of each type of incidence. You can record this figure within the small box given for the appropriate day, and
  - record the number of occupied beds.
- You may want to record additional information about each incident. For example, a brief description, date, time and staff initials. The table below can be used alongside the safety cross to record this information.
- At the end of each month, your completed safety cross should be shared with your lead coach (this can be done by taking a photograph and sending by email). It is recommended that you keep all completed Safety Crosses for your own records.

It is a good idea to let staff and residents or patients know how many days have gone by without an incident in the care home or hospital ward. For example, you can do this by simply stating in a public area 'It has been ___ days since there has been a fall in this care home or hospital ward'. This information would be updated daily.

Adapted from Healthcare Improvement Scotland Pressure Ulcer safety cross.

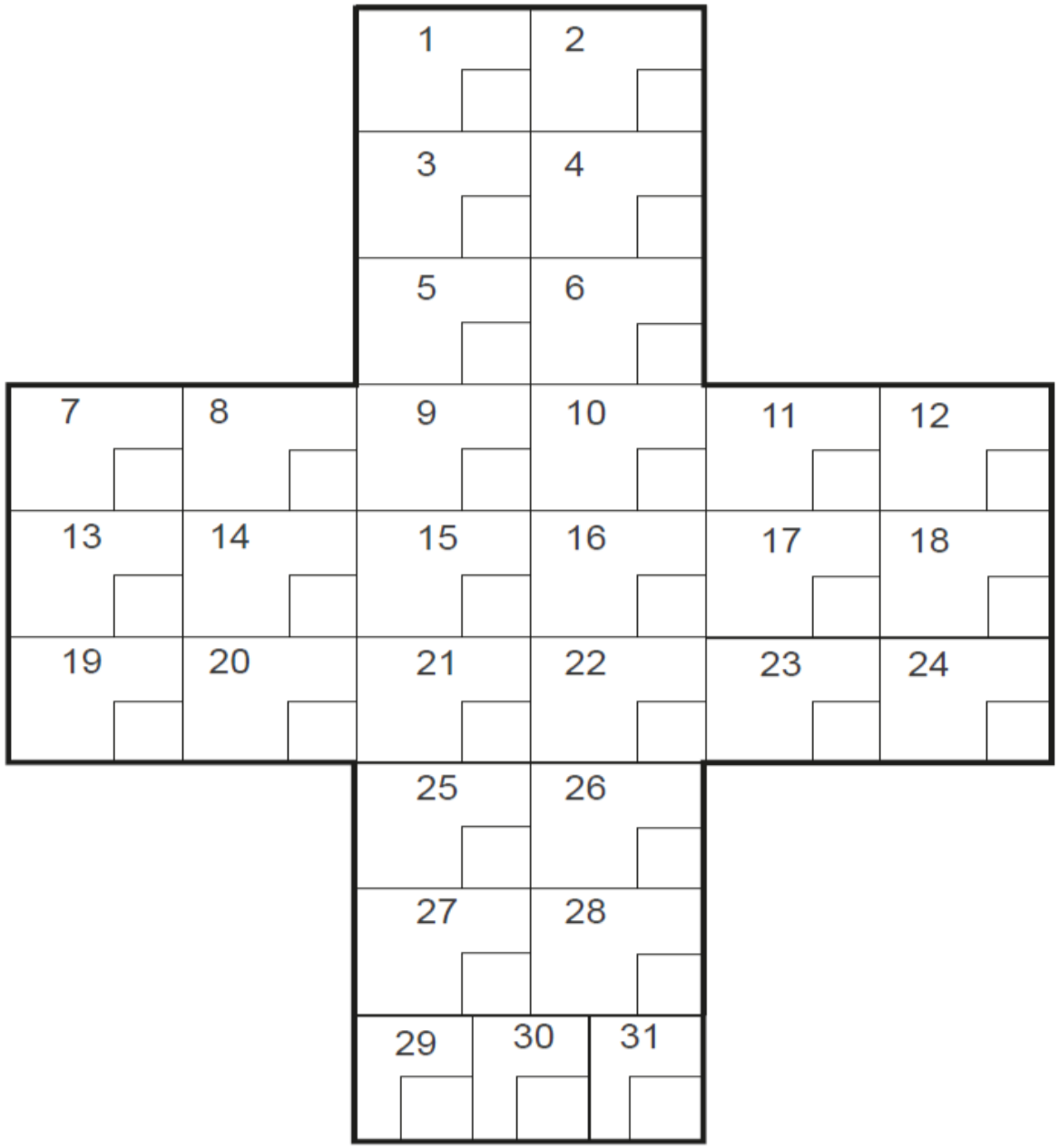
Safety Cross

Month:	
Year:	
Care home/ hospital ward:	

Incidence of stress and distress occurred	
Fall occurred	
PRN psychoactive medication administered	
Hospital admission (care homes only)	

Record instances of an event

- Write the number of occupied beds for each day
- If there is only one incidence of an event, no number needed
- If there is more than one instance, write the number of incidences in the relevant colour



Room no	Initials	Brief incident bullet points followed by brief action taken	Date, time and staff initials

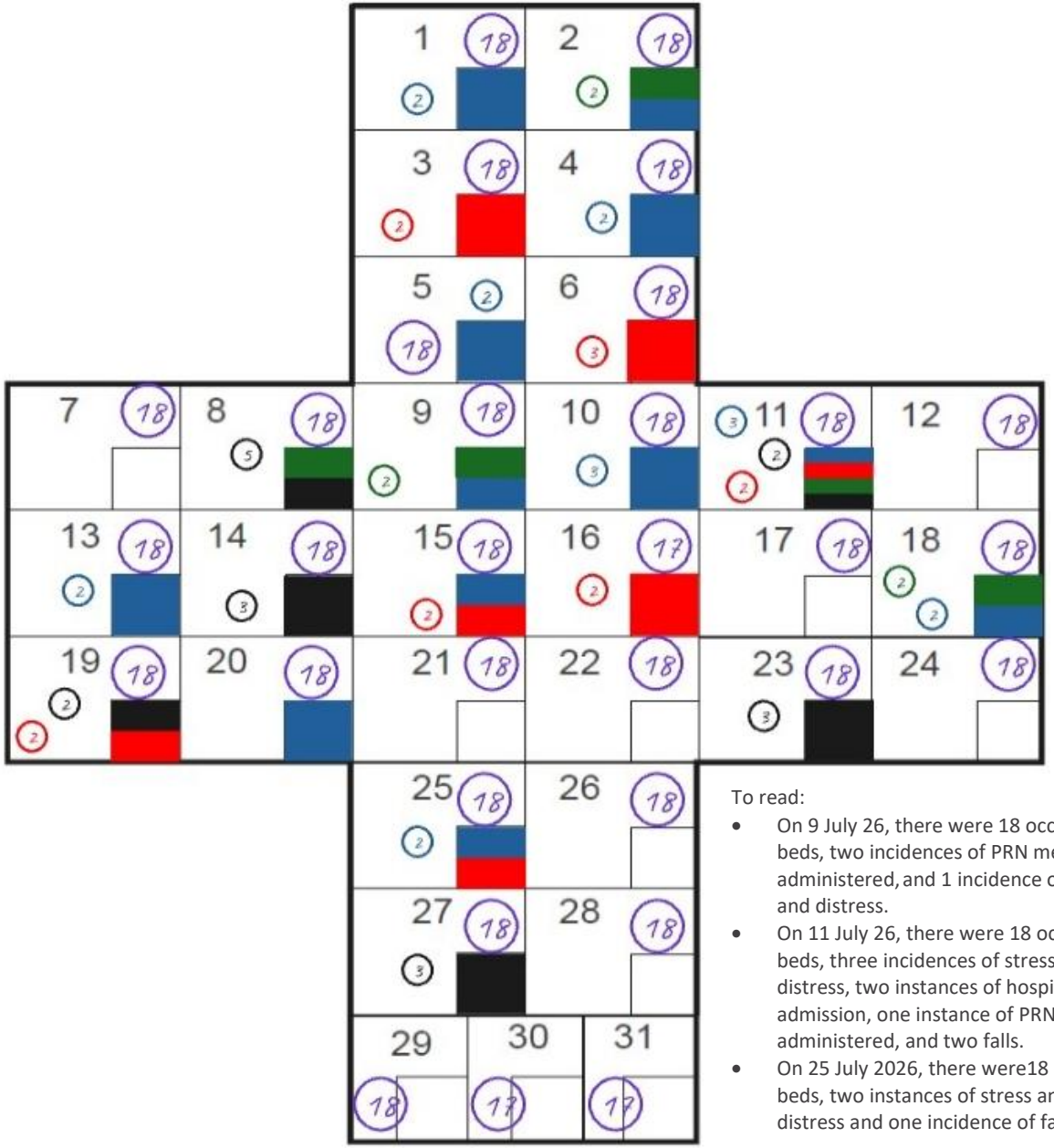
Example of a completed Safety Cross

Month	July
Year	2026
Care home/ hospital ward:	ABC Ward, XYZ hospital

Stress and distress occurred	
Fall occurred	
PRN psychoactive meds administered	
Hospital admission	

Record incidences of an event

- Write the number of occupied beds for each day
- If there is only incidence of an event, no number needed
- If there is more than one incidence, write the number in the relevant colour



To read:

- On 9 July 26, there were 18 occupied beds, two incidences of PRN meds administered, and 1 incidence of stress and distress.
- On 11 July 26, there were 18 occupied beds, three incidences of stress and distress, two instances of hospital admission, one instance of PRN meds administered, and two falls.
- On 25 July 2026, there were18 occupied beds, two instances of stress and distress and one incidence of fall.

Contact us

Get in touch to provide feedback or share your plans for using the reducing stress and distress toolkit. Your query will be directed to the appropriate contact at Healthcare Improvement Scotland, Care Inspectorate or NHS Education for Scotland.

Email: his.focusondementia@nhs.scot

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Need information in a different format? Contact our Equality, Inclusion and Human Rights Team to discuss your needs. Email his.equality@nhs.scot or call 0141 225 6999. We will consider your request and respond within 20 days.

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