Self-evaluation tool for reducing stress and distress for people living with dementia

A quality improvement framework

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Introduction

This tool sets out what is expected from high-quality, person-centred care to enable good outcomes for people living with dementia and their carers[1]. It enables staff, managers and leaders in hospital and care home services to identify areas of good practice and areas for improvement. This includes specialist dementia units, acute and community hospitals, and care homes given the high numbers of people living with dementia in these settings at any one time[2]. It summarises what we know about how person-centred approaches can prevent and support stress and distress for people living with dementia.

Improving experience and outcomes for people living with dementia in hospitals and care home settings through the development of high-quality, person-centred care remains a priority of the dementia strategy for Scotland. This tool support teams to evidence implementation of relevant standards and guidelines, such as SIGN guideline on dementia, Ageing and Frailty Standards and Health and social care standards: my support, my life and aligns with the Care Inspectorate approach to Self-evaluation for improvement. The tool works within the principles of the Adults with Incapacity (Scotland) Act 2000 and the Mental Health (Care and Treatment) (Scotland) Act 2003.

Healthcare Improvement Scotland, Care Inspectorate, and Mental Welfare Commission for Scotland continue to highlight the need for support to improve person-centred planning across health and social care settings and the engagement of carers. Providing person-centred approaches that prevent and support stress and distress can lead to better outcomes for people. It can also help to avoid admission or readmission to hospital, enable timely discharge and effective transitions of care between hospital, home or care home settings.

This framework is intended for use as a reflective tool for teams to self-evaluate their current services and identify how to build on what they are currently doing well, and what areas they should consider as a focus for improvement.

[1] 'carers' are defined as those who provide care and support to family members, friends, and neighbours.
[2] While this tool was primarily designed and tested in hospital and care home settings, it can be adapted for other health and social care settings where people living with dementia are supported

Background

We have captured learning through working with teams across Scotland to support improvement in the provision of high-quality care for people living with dementia. Key resources that have been developed include:

- Six high impact changes to support people living with dementia in hospitals
- My life, my care home
- Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families and carers

The combined learning from our programmes has informed this framework. We also gathered views and feedback from experts including those with clinical and professional expertise and people with lived experience.

Why do we need this framework?

It is estimated that around 25% of people in acute hospitals and 62% care home residents have dementia[3]. We know that people living with dementia often experience longer hospital stays, delays in leaving hospital and reduced independent living. Up to 90% of people living with dementia will experience stress and distress and this can be exacerbated when in unfamiliar environments, which includes hospitals and care homes[4]. Distress can also lead to increased safety issues, such as falls. Many people who do not have a diagnosis of dementia, will also experience distress due to cognitive impairment, delirium, or other factors.

Staff require high levels of confidence and skill to best support people with symptoms of stress or distress. While there are some examples of good practice, it is an area of significant challenge. There can be a reliance on pharmacological solutions, the side effects of which may exacerbate impairments in cognitive functioning and lead to wider safety issues, such as increased risk of falls. Traditional one-to-one observation may be used in other cases. These approaches are costly when person-centred preventative strategies would have been more appropriate. These findings are consistent with Healthcare Improvement Scotland quality assurance visits to acute general hospitals, the Mental Welfare Commission for Scotland reports on specialist dementia units and community hospitals and Care Inspectorate assurance visits to care homes.

[3] Public Health Scotland. Care home census for adults in Scotland - Statistics for 2012 – 2022 [online]. 2022.
[4] St John K, Koffman J. Introducing Namaste Care to the hospital environment: a pilot study [online]. 2017

Principles of a person-centred approach to stress or distress

This framework focuses on the prevention, early recognition and response to stress and distress using person-centred approaches. The principles for this approach have been developed based on key guidance such as Health and Social Care Standards, SIGN guidelines and Promoting Excellence and include the following.

- Understanding the lived experience of people living with dementia and their carers and engaging their participation, consent and choice about treatment and care.
- Creating dementia friendly physical environments that are fit for purpose, therapeutic and hazard free.
- Creating a culture that values anticipation, early recognition of deterioration and triggers for stress.
- Consideration of factors that may lead to or worsen the person living with dementia's distress, such as pain, constipation, infection or medication.
- Embedding a human rights-based approach to care including the Charter of Rights for people living with dementia and their carers.
- Introducing education, training and supervision for staff to ensure they have the knowledge and skills to deliver high-quality care.

Observation practice

This framework includes criteria for one-to-one observation practice, also known as enhanced observations. One-to-one observation is the scaling up of contact provided by staff supporting and caring for the person living with dementia. It may be required if the person cannot be safely left on their own for short periods of time. In some areas there is a move towards a more person-centred, flexible and therapeutic approach to observation practice and the terminology 'continuous observation' is used. When one-to-one observation is required, staff should continue to follow, or adapt, the person's individualised care plan. This will ensure that their health and wider care needs are responded to. Staff should adhere to the approaches outlined in Mental Welfare Commission's Rights, Risks and Limits to Freedom Good Practice Guide to ensure the least restrictive approach is taken, that does not stop the person making choices, moving around or undertaking the activities they want.

How to use the self-evaluation tool

The self-evaluation tool can be used by teams to self-assess their service against a set of quality criteria. The criteria are based on what we have learned is important in the prevention and management of stress and distress based on person-centred approaches.

This can be completed as a service development activity and can be an internal process or facilitated by someone who is not normally part of the team. It should involve all key professions involved in the delivery of care including nurses, allied health professionals, care home support staff, managers and doctors. It is recommended to involve people with dementia and carers in the self-evaluation process.

The self-evaluation tool can be printed and completed by hand or an editable version has been created to allow completion using a computer or tablet. To download the relevant version of the tool use the links below:

- Reducing Stress and Distress Self-Evaluation tool: printable version
- Reducing Stress and Distress Self-Evaluation tool: editable version

There is a column against each criterion to rate current practice on a scale from 1-6.

1. Unsatisfactory: urgent remedial action required
2. Weak: priority action required
3. Adequate: strengths just outweigh weaknesses
4. Good: important strengths, with some areas for improvement
5. Very Good: major strengths
6. Excellent: outstanding or sector leading

There are additional columns for providing evidence and identifying initial improvement ideas. All sub-criteria have suggested evidence sources which can be used to complete the evidence column (see Appendix 1). Not all evidence examples will be relevant to your workplace and it is expected that teams identify their own sources of evidence. Evidence should demonstrate that the views of staff, people living with dementia and carers have been included.

An improvement plan with the top three priorities a service wishes to improve can then be developed (see Appendix 2 for an improvement plan template). The tools Further tools and resources to support teams using the framework can be found in Appendix 3.

Reducing stress and distress self-evaluation tool

The table below is for information only. To complete the tool use the links on page 5

1. There are effective processes for the assessment and early recognition of stress and distress			
a.	**Staff follow a structured and holistic approach when anticipating, preventing, and assessing distressed behaviours in people living with dementia**		
	Rate 1-6	**Evidence**	**Improvement ideas**
b.	**The environment is dementia friendly, therapeutic, and as far as possible, hazard free**		
	Rate 1-6	**Evidence**	**Improvement ideas**
c.	**There are regular team* reviews to support early recognition and response to stress to prevent its escalation**		
	Rate 1-6	**Evidence**	**Improvement ideas**
d.	**Information is shared across teams* using written and verbal formats (such as safety briefings or huddles during each shift) to facilitate rapid communication about people living with dementia who are experiencing stress and distress** **The team includes the broad range of professions involved in care and will be dependent on care setting and the needs of the individual*		
	Rate 1-6	**Evidence**	**Improvement ideas**

2. Person-centred care plans are developed and used to inform care **Person-centred care plan may be called a care plan or personal plan depending on setting*			
a.	**Staff use best practice guidance in person-centred care planning**		
	Rate 1-6	**Evidence**	**Improvement ideas**
b.	**There is a team approach to person-centred care planning and delivery**		
	Rate 1-6	**Evidence**	**Improvement ideas**
c.	**Existing processes are used to support person-centred care planning**		
	Rate 1-6	**Evidence**	**Improvement ideas**
d.	**Person-centred information is integrated into care plans and consistently available to all team members to inform care**		
	Rate 1-6	**Evidence**	**Improvement ideas**

3. Meaningful activity and/or connections are provided to prevent and support stress and distress **Meaningful activity is one that has been identified by the person living with dementia and/or their carers rather than one that is routinely provided to all patients/residents*			
a.	**Meaningful activity is identified and offered in line with the care plan**		
	Rate 1-6	**Evidence**	**Improvement ideas**
b.	**Processes are in place to ensure the whole team are aware of the importance of meaningful activities and connections identified for individuals and know how to support**		
	Rate 1-6	**Evidence**	**Improvement ideas**
c.	**Identified meaningful activities and connections are flexible and respond appropriately to the wider health, treatment and wellbeing needs of the person living with dementia**		
	Rate 1-6	**Evidence**	**Improvement ideas**
d.	**Evidence that the environment supports the delivery of a range of activity to support stress and distress**		
	Rate 1-6	**Evidence**	**Improvement ideas**

4. Reducing stress and distress through one-to-one observation (may be required when the person cannot be safely left on their own for short periods of time)			
a.	Any proposed one-to-one observation follows a period of more frequent interaction and builds on the person's existing care plan		
	Rate 1-6	Evidence	Improvement ideas
b.	Restrictive practice during one-to-one observation is trauma informed and minimised. Any restriction to privacy is justified and documented based on assessment of immediate, significant risk of harm. Any periods of one-to-one observation are brief, regularly reviewed, and monitored to ensure this does not cause more distress		
	Rate 1-6	Evidence	Improvement ideas
	There is a review process for people living with dementia requiring one-to-one observation – the purpose and nature are reviewed every 8-12 hours (minimum) by the team		
	Rate 1-6	Evidence	Improvement ideas
c.	There is evidence of meaningful activity and connection being planned and offered during periods of one-to-one observation. This should be directly linked to the person's care plan and health and care needs		
	Rate 1-6	Evidence	Improvement ideas

5. Carers are identified, involved and their needs are supported within approaches to reduce and support stress and distress			
a.	Carers are consistently identified, and information recorded		
	Rate 1-6	Evidence	Improvement ideas
b.	Carers are involved meaningfully in assessment, care planning and review processes as partners in care		
	Rate 1-6	Evidence	Improvement ideas
c.	Carers are supported to identify and support stress and distress		
	Rate 1-6	Evidence	Improvement ideas
d.	The wider needs of carers are identified and supported to enable the caring role to be maintained and support the transition of care		
	Rate 1-6	Evidence	Improvement ideas

6. All staff feel confident, competent, and supported to use person-centred approaches			
a.	**The team is able to show evidence of applied knowledge and skills to deliver person-centred care as outlined in the Promoting Excellence framework. This should be at the levels appropriate for their role and nature of contact with people living with dementia**		
	Rate 1-6	**Evidence**	**Improvement ideas**
b.	**The team have the knowledge and skills to respond appropriately to stress and distress as outlined in the Promoting Excellence framework This should be at the levels appropriate for their role and nature of contact with people living with dementia**		
	Rate 1-6	**Evidence**	**Improvement ideas**
c.	**The team have the knowledge and skills to deliver trauma informed care as outlined in the Transforming Psychological Trauma Knowledge and Skills Framework*. This should be at the levels appropriate for their role and nature of contact with people living with dementia** **The workforce ensures that the needs of children and adults who are affected by trauma are recognised, understood and responded to in a way which recognises individual strengths, acknowledges rights and ensures timely access to effective care, support and interventions for those who need it*		
	Rate 1-6	**Evidence**	**Improvement ideas**
d.	**There is effective line management and clinical supervision in place to support staff who work with people living with dementia who experience stress and distress**		
	Rate 1-6	**Evidence**	**Improvement ideas**
e.	**Local dementia experts and other leaders support staff development activities and sharing of learning about dementia care in practice**		
	Rate 1-6	**Evidence**	**Improvement ideas**

f.	Staff are supported to identify, test and implement improvements		
	Rate 1-6	**Evidence**	**Improvement ideas**

Appendix 1: Examples of suggested evidence

1. There are effective processes for the assessment and early recognition of stress and distress	
a.	1. Evidence of carer involvement within assessment process. 2. Individual records evidence consistent use of agreed tools for assessment, prevention and management of stress or distress. 3. Recorded information is accessible to staff of which assessment tools have been agreed for use.
b.	1. The environment design is dementia friendly. *2.* Evidence that the team use methodology, such as use of the King's Fund Environmental Assessment tools to audit the environment design.
c.	1. An agreed process for review is in place – this may be evidenced in a standard operating/operational procedure. 2. Individual records evidence regular team reviews.
d.	1. Records of safety briefings and huddles show evidence of use of effective communication tools such as SBAR. 2. During staff handover there is evidence of information shared regarding support put in place to respond to stress and distress and any further action required.
2. Person-centred care plans are developed and used to inform care	
a.	1. Evidence that staff have been trained in best practice on person-centred care planning such as Mental Welfare Commission guide on person-centred care plans or Care Inspectorate Guide for Providers on Personal Planning. 2. Evidence in care plans that staff have applied their knowledge and skills (from training such as Promoting Excellence Framework or Transforming Psychological Trauma Knowledge and Skills Framework) to deliver person-centred care. 3. Evidence that staff are aware and confident in communicating with individuals in their preferred communication format. 4. Evidence that the care/personal plan has been implemented.
b.	1. Clear roles and responsibilities for involvement in care plans/personal plans are recorded, such as a standard operating/operational procedure. 2. Information is recorded centrally and is accessible to the whole team. 3. Processes are in place for escalation to other relevant professionals, such as psychology referral process.
c.	1. Process for carers to share person-centred information during admission for example in person-centred planning document such as Getting to Know Me. *2.* Process in place to review and update person-centred information.

d.	1. Person-centred information is shared and accessible to all members of the team, for example, recorded on bedside posters where appropriate or in shared notes. 2. Evidence that information captured in Getting to Know Me is used to inform the care plan. 3. Evidence that staff are aware of and know where to access the care plans for people in their care. 4. Evidence of regular review or evaluation to ensure appropriate support and identify if further action required.
3. Meaningful activity and/or connections are provided to prevent and support stress and distress	
a.	1. Evidence in care plan of meaningful activity being identified through conversation with person with dementia and their carers. 2. Evidence that identified activity has been offered. 3. The impact of engaging in meaningful activity is recorded. 4. Evidence that the important people in an individual's life are included and supported to connect with them.
b.	1. Information in individual records about meaningful activities and connections for people living with dementia that can be supported by all members of the team, for example, use of an activity planner to lay this out. 2. Shared individual records are used to increase communication across the team. 3. Information in individual records that demonstrate different staff are involved in providing meaningful activity and connections.
c.	1. Evidence in documents that record how and why interactions are delivered and adapted based on the person living with dementia's ongoing assessed needs. 2. There is a risk enablement approach to activity.
d.	1. Evidence of a list of a range of activities that are available in the service area, for example rummage boxes, sensory items, relaxing music or activities.
4. Reducing stress and distress through one-to-one observation	
a.	1. Care planning in place for one-to-one observation is linked to main care plan. 2. An agreed process is in place covering pathway for one-to-one observation – this may be evidenced in a standard operating/operational procedure.
b.	1. Evidence of least restrictive practice. For example, where noise is a cause of stress and distress, the person may be supported in quieter areas of ward or care home and is not automatically kept in their room or without access to outdoor spaces. 2. Staff are aware of potential triggers and these are in one-to-one observation care plan. 3. Individual records have evidence of regular reviews of any restrictive practice. *4.* Reviews include details and justification of any restrictive practice and how this is trauma informed.

c.	1. Individual records include evidence of team reviews taking place at minimum 8–12-hour periods.
d.	1. Individual records include details of how periods of one-to-one observation have been planned and are adapted in line with the person's existing care plan. 2. Individual records include daily evidence of engagement in meaningful activities in line with the person-centred care plan.
5. Carers are identified, involved and their needs are supported within approaches to reduce and support stress and distress	
a.	1. Individual records include details of identified carers. 2. Information is recorded on power of attorney and welfare proxies/guardianship. 3. Staff aware of definition of 'carer' and what this means to their practice. 4. Information for carers is available, for example, notice boards, leaflets. 5. Staff have completed Equal Partners in Care (EPIC) training.
b.	1. Individual records include details of carer involvement in assessment, care planning and review processes. 2. There is clear process for involving carers in completing a Getting to Know Me document, for example, it is included in the admission process. 3. Evidence in individual records that carers have been offered choice of how and when to be involved. 4. Evidence in individual records of open and transparent communication with carers. 5. The service operates person-centred visiting and there is clear and accessible information about this for all visitors. 6. Carer feedback indicates they feel their caring role is valued by staff. Can be captured by Care Opinion, comments / complaints, thank you cards.
c.	1. Evidence that information is shared with carers regarding approaches to support stress and distress. 2. Range of tools and resources available for signposting. 3. Training provided for carers to support their role.
d.	1. Evidence that carer health and wellbeing needs are identified. 2. A single point of contact is established for carers. 3. A pathway for referral to local carer services/carer support worker is in place.
6. All staff feel confident, competent, and supported to use person-centred approaches	
a.	1. Evidence in care plans/personal plans that staff have applied the knowledge and skills learnt to enable early recognition and assessment of stress and distress in the people they are looking after for example use of pain assessment chart. 2. Evidence in care plans/personal plans that staff have applied the knowledge and skills learnt to enable a care approach that is outcome focused.

	3. All staff have a personal development plan which includes training to the relevant level of the Promoting Excellence Framework and how they use the training in practice. 4. A team or department training and development plan sets out a range of learning and development opportunities. 5. Regular personal development reviews for all staff. 6. Regular observation of staff practice.
b.	1. Evidence that staff have access to NHS Education for Scotland (NES) / Scottish Social Services Council (SSSC) resources as appropriate for example Dementia Standards: Supporting Change Tool. *2.* Staff rotas allow protected time to access training and development activities including self-directed learning opportunities in line with personal development plans.
c.	1. Staff have completed relevant training related to trauma informed care. *2.* Staff can evidence they have applied their trauma informed knowledge and skills to deliver person-centred care in care plans/personal plans.
d.	1. Staff records include evidence of regular supervision for all relevant staff. 2. Evidence of regular clinical supervision delivered by someone who is appropriately trained, such as complex case discussion forum, reflective practice, debrief after a serious incident.
e.	1. Evidence that the area of practice where possible, have engaged with established experts in the field of dementia such as Dementia Consultants and Dementia Specialist Improvement Leads to support dementia education for staff. 2. Dementia Champions are in place within the area of practice or staff are able to access their support. 3. Dementia Ambassadors are in place and have been trained to the appropriate level as recommended by SSSC. 4. Both the Dementia Champions and Dementia Ambassadors participate in the wider network opportunities available. 5. Dementia Champions/Ambassadors and Dementia Specialist Improvement Leads have protected time to support team development.
f.	1. Evidence of structured quality improvement work and improvement data are recorded and shared. 2. Current quality improvement work is displayed on an improvement noticeboard. 3. Staff information networks that share news about improvement work and development opportunities. 4. Learning events are available and accessible for all team members.

Appendix 2: Improvement plan template

Service name		**Date:**	
The top three priorities for improvement	**Lead**	**By when**	**Completed**
Any other improvements	**Lead**	**By when**	**Completed**

Appendix 3: Tools and resources

Resource	Source	What it is and what it's for
Care Opinion	Care Opinion	An online platform for people to share their experiences of health and care to lead to learning and change in a safe and simple approach.
Dementia "A once for Scotland" learning site on TURAS Learn	NHS Education for Scotland	A learning site containing a suite of resources to support the workforce to gain the knowledge and skills within the Promoting Excellence framework to support people with dementia and their families and carers to have the best quality of life possible.
Dementia Champions Programme	University of West of Scotland (commissioned by NHS Education for Scotland on behalf of the Scottish Government)	A programme aimed at staff working in acute hospital care and associated services. It aims to support further development in the knowledge, skills, values and attitudes at the enhanced level of Promoting Excellence.
Dementia Improvements in Specialist Dementia Care	University of the West of Scotland	Dementia Specialist Improvement Leads (DSILs) improving care and support for people with dementia, their families and carers in Scotland A programme designed for health and social care staff, set at the expertise level of Promoting Excellence. It aims to build the capacity of participants to enable them to take forward workforce education and training and service development to support implementation of the Promoting Excellence Framework.
Dementia Standards: Supporting Change Tool	NHS Education for Scotland	This tool is designed to facilitate change and improvements in services and practice against the Standards of Care for Dementia in Scotland. The tool offers staff an opportunity for self-assessment of their care setting.
Dementia Skilled Improving Practice: Learning Resources	NHS Education for Scotland	Resource for health and social service workers to develop and improve staff knowledge, skills and confidence in the work they are doing to support people with dementia, and their families and carers. This resource will develop understanding

		about dementia, and support staff to think differently about the people with dementia they work with.
Enhancing the Healing Environment	The King's Fund	A range of resources, including assessment tools, to enable hospitals, care homes, primary care premises and specialist housing providers to become more dementia friendly.
Getting to Know Me	Alzheimer Scotland	A downloadable PDF to support hospital staff to gain better understanding of patients with dementia. The document is designed to be completed by a person living with dementia, or a carer or relative.
Guide for Providers on Personal Planning	Care Inspectorate	A document to support staff in services to develop personal plans for adults.
Meaningful Connection in Care Homes: Self-evaluation tool	Care Inspectorate	A self-evaluation tool to help evaluate and support meaningful connection for people living in adult and older people's care homes and identify any areas of improvement.
National Trauma Transformation Programme	NHS Education for Scotland	Trauma training resources from the National trauma training programme that are available to support all members of the Scottish workforce.
National Trauma Transformation Programme: A Roadmap for Creating Trauma-informed and Responsive Change	Scottish Government	A Roadmap for Creating Trauma-informed and Responsive Change. Guidance for organisations, systems and workforces in Scotland.
Person-centred care plans: Good practice guide	Mental Welfare Commission for Scotland	Guidance on good practice in the development of person-centred care plans for people using mental health, dementia and learning disability services.
Promoting Excellence Framework	Scottish Government / NHS Education for Scotland	Web page-based knowledge and skills framework. The framework is for all health and social services staff working with people living with dementia and carers.
Right to Treat?	Mental Welfare Commission for Scotland	Guidance on delivering physical healthcare to people who lack capacity and refuse or resist treatment.

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