

Focus on Dementia Learning System event in partnership with the Scottish Intercollegiate Guidelines Network (SIGN)

SIGN Dementia Guideline

Thursday 7 December 2023 14:00 – 15:30





Welcome

Lynn Flannigan

Senior Improvement Advisor Healthcare Improvement Scotland



Agenda

TIME	TITLE	PRESENTER
14:00	Welcome and introductions	Lynn Flannigan Senior Improvement Advisor, Healthcare Improvement Scotland
14:05	Ministerial video	Maree Todd Minister for Social Care, Mental Wellbeing and Sport Scottish Government
14:15	Background and rationale	Dr Adam Daly Associate Medical Director, North Lanarkshire Health and Social Care Consultant in Old Age Psychiatry Dementia SIGN Development Group Chair
14:30	Involvement of people with lived experience	Karen Graham Patient Involvement Advisor, SIGN Marion Ritchie National Dementia Carers Action Network
14:45	Overview of guideline	Dr Adam Daly
15:00	Right Decision Service	Ann Wales Programme Lead, Healthcare Improvement Scotland
15:10	How the work of Focus on Dementia is supporting implementation of some key recommendations • post-diagnostic support • management of stress and distress/person-centred care planning in hospitals	Julie Miller Improvement Advisor, Healthcare Improvement Scotland Marie Innes Senior Improvement Advisor, Healthcare Improvement Scotland
15:25	Next steps and evaluation	Lynn Flannigan
15:30	Close	

Maree Todd Minister for Social Care, Mental Wellbeing and Sport





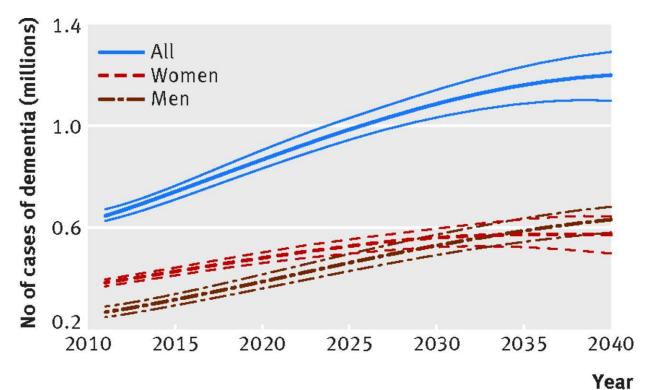


SIGN Dementia Guideline

Background and rationale

Dr Adam Daly Guideline Development Group Chair

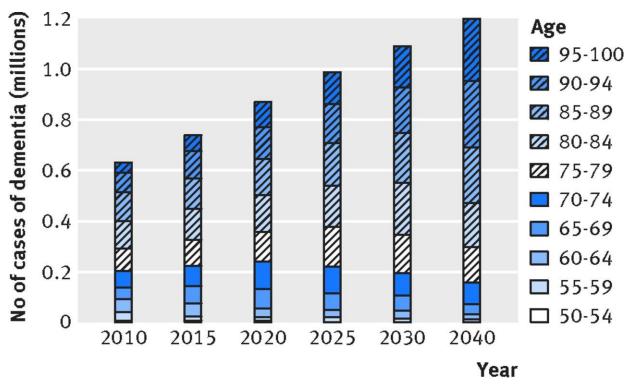
Fig 2 Projected number of people with dementia in England and Wales 2011-40.



Sara Ahmadi-Abhari et al. BMJ 2017;358:bmj.j2856



Fig 3 Age specific estimated number of cases of dementia 2010-40 in men and women.



Sara Ahmadi-Abhari et al. BMJ 2017;358:bmj.j2856



The need for this guideline

Variations in practice across Scotland includes:

services and pathways for people with young onset dementia

treatment of cognitive and non-cognitive symptoms in dementia

psychological approaches

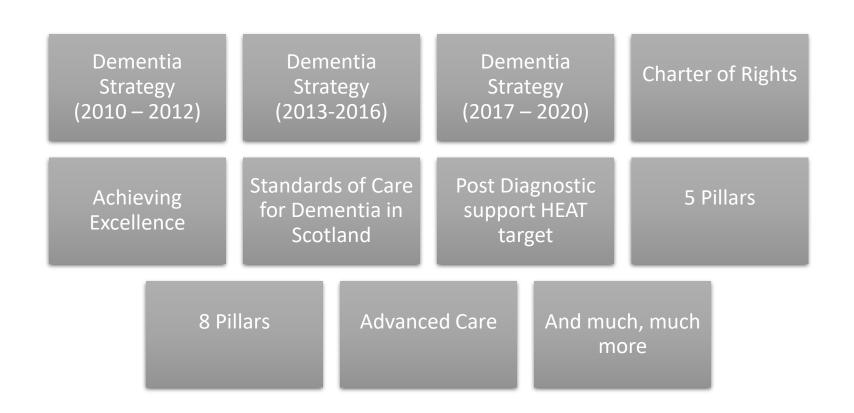
management of stress and distress

Aim of the guideline

Aims

- to provide evidence-based recommendations on
 - Assessment
 - Diagnosis
 - care and support for people with dementia and their carers
- to inform and provide benefit to all stakeholders, ensuring
 - timely, person-centred interventions and
 - efficient utilisation of resources

Progress and Strategic Driver Since 2006



Proposing a SIGN Guideline

- Joint application
 - Royal College of Psychiatrists in Scotland
 - Alzheimer's Scotland Nurse/AHP Dementia Consultants
- 20 years since the last Scottish Clinical Guideline
- Strong desire from professionals

Challenges

Limited resources

Staff pressures

NICE 97

Poll – how many people were needed on this guideline?

A poll will appear on the main screen

Please choose the option you think is correct

Answer

More than 30!

Dementia guideline development group

Consultant In Old Age Psychiatry

General Practitioner

> Clinical Psychologist

People with lived experience

Consultant Neurologists

Allied Health Professionals

Consultant in Medicine for the elderly

Consultant Physicians

Radiologist

SIGN

Academic Clinicians

Group members

- Dr Adam Daly (Chair) Consultant (Old Age) Psychiatrist, NHS Lanarkshire
- Dr Lyndsay Alexander Academic Team Lead, Research, School of Health Sciences, Robert Gordon University
- Dr Paul Baughan GP and National Clinical Adviser for Ageing and Health, CMO Directorate, Scottish Government
- Prof Kay Cooper Clinical Professor Allied Health Professions, Robert Gordon University/ NHS Grampian
- Dr Stephanie Crawford Consultant Clinical Psychologist, NHS GG&C
- Ms Ray Fallan Network and Growth Officer, TIDE
- Ms Naomi Fearns Health Service Researcher, Healthcare Improvement Scotland
- Ms Lynn Flannigan Senior Improvement Advisor, Healthcare Improvement Scotland
- Ms Sarah Florida James Programme Manager, SIGN, Healthcare Improvement Scotland

- Dr Claire Gall Consultant Neurologist, NHS GG&C
- Dr Caroline Gallacher GP, NHS Lothian
- Ms Suzanne Gray Alzheimer Scotland Dementia Consultant, NHS Tayside
- Dr Rhiannon Howie-Davies Consultant Clinical Psychologist, NHS Tayside
- Dr Ravi Jampana Neuroradiologist, NHS GG&C
- Prof Gregory Lip Consultant Cardiologist (Hon), Liverpool Heart & Chest Hospital NHS Trust
- Dr Graham Mackay Consultant Neurologist, NHS Grampian
- Dr Louise McCabe Senior Lecturer in Dementia Studies, University of Stirling
- Ms Kanide Manji Head of Dementia, Age Scotland
- Dr Vivek Pattan Consultant, Psychiatry of Old Age, NHS Forth Valley
- Dr Carol Quinn Consultant, Older Age Psychiatry, NHS GG&C

- **Dr Terry Quinn** Geriatrician, Reader and Associate (School of Medicine, Dentistry & Nursing), Glasgow University
- Ms Marion Ritchie Lay Representative, Committee Member-NDCAN and Former Carer
- Dr Roy Soiza Consultant Physician, NHS Grampian
- Dr Joanna Shim Allied Health Professions Research Fellow, Robert Gordon University, Aberdeen
- Ms Christine Steel AHP Consultant, Dementia, NHS GG&C
- Ms Jacqueline Thompson Nurse Consultant, Care of the Elderly/Frailty, North Cumbria Integrated Care Trust
- Dr Katharine Thompson Consultant, Palliative Medicine, NHS Tayside
- Prof Debbie Tolson Alzheimer Scotland Professor of Dementia, University of the West of Scotland



Involvement of people with lived experience in SIGN Guideline on Dementia

Karen Graham Patient Involvement Advisor, SIGN

Marion Ritchie National Dementia Carers Action Network



Engagement with third sector organisations

- Alzheimer Scotland
- Alzheimer Scotland's National
 Dementia Carers Action Network
- Carers Scotland
- Carers Trust Scotland, Carer Voices (The Alliance)
- Tide
- Age Scotland
- About Dementia

- Life Changes Trust
- Scottish Dementia Working Group
- Alzheimer's Society
- Young Dementia UK
- Minority Ethnic Carers of People Project
- LGBT Health and Wellbeing
- Scottish older people's assembly

Key issues highlighted from submissions

- Support and training for carers
- Education for healthcare professionals
- Communication with people with dementia and their families
- Who should communicate diagnosis of dementia
- Post-diagnostic support for person and carers
- Information needs throughout care
- Equal partnerships and involvement of person with dementia
- Transition between settings and support

Representation on guideline group

1 representative from third sector organisation



2 carer representatives





Direct engagement with people with dementia

- Meeting with Scottish Dementia Working Group members to discuss what matters most to people (5 members)
- Meeting with About Dementia, Age Scotland members to discuss draft section of 'Provision of information' to get their views (6 members)
- Organised a consultation meeting "pre meet" to support people to participate in consultation meeting (20 people attended)
- Ran workshop specifically for people with dementia and carers to get feedback on guideline
- Invited individuals with dementia to peer review guideline (1 person participated)

Person-centred guidance

- Issues from third sector organisations reflected in KQs
- KQs changed/added to reflect concerns of carers on guideline group
- Provision of information section changed to include issues of importance to people with dementia and carers
- Infographic in guideline on post-diagnostic support changed to reflect views of people with dementia

Involving people with dementia and carers in development of plain language version

- Meeting with people with dementia and carers to discuss preferences for plain language version of guideline (13 participants)
- Pre-consultation meeting (15 participants)
- Consultation (11 participants)









Lived Experience perspective



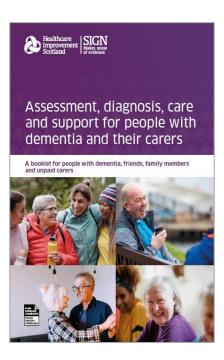


Lived experience perspective





Patient Version of Guideline





SIGN Dementia Guideline

Recommendations

Dr Adam Daly Guideline Development Group Chair

SIGN Dementia Guideline

Section Overviews

Recommendations

Call to action

Interesting points

Pre-Covid Acceptance

Covid Delays and opportunities

1st SIGN Guideline conducted entirely remotely

1st SIGN guideline to be 50% Qualitative

Definitions

Dementia

YOD

Stages of Dementia

Multi-professional/sector approach

Healthcare professional

Carer/young carer

The guideline

• Note: 116 pages cannot be summarised well in 15 minutes

Recommendations

- 121 points in total
 - 67 Recommendations
 - 6 Key recommendations
 - 43 Good Practice Points
 - 11 Information points

What is the most important thing for dementia guidance to cover?

A poll will appear on the main screen

Please type **one word** into the poll as your answer

The Sections

- The start
 - 1. Introduction
 - 2. Key Recommendations
- The Evidence and full recommendations
- The end
 - 9. Provision of Information
 - 10. Implementing the Guideline
 - 11. The Evidence Base
 - 12. Development of the Guideline

3 Identification and diagnosis of dementia

3.1 Identification and assessment of suspected dementia

- History and examination
- In person vs remote
- Cognitive Testing

3.2 Discussing a diagnosis of dementia

- Who to involve
- When
- How

Key recommendation 1:Identification and diagnosis of dementia

Healthcare professionals should ensure that the discussion of a diagnosis of dementia should include positive and hopeful, yet realistic, messages; information on prognosis and sources of support; information on wellbeing and how the person with dementia can continue with their life, maintain their sense of self and accept their identity as someone with dementia.

Key recommendation 2: Anticipatory (Future) care planning

Anticipatory care planning may involve a series of conversations over time, to allow clarification, reflection and updates to the plan to reflect any changing needs. Early discussions are beneficial, as the capacity of the person with dementia diminishes as the disease progresses.

Anticipatory Care Planning decisions should be reviewed and updated; the frequency of this will be influenced by the pace of disease progression and any changing needs.

4 Further investigative procedures

- 4.1 Diagnosing suspected Alzheimer's disease
 - Structural and functional imaging, CSF
- 4.2 Diagnosing suspected frontotemporal dementia
- 4.3 Diagnosing suspected vascular dementia
- 4.4 Diagnosing suspected dementia with Lewy bodies
- 4.5 Consideration of genetic testing

5 Post diagnostic support

- 5.1 Experiences of post-diagnostic support
- 5.2 Needs and unmet needs from post-diagnostic support
- 5.3 Access to post-diagnostic support for ethnic minority groups
- 5.4 Continuity of care needs and models of delivery
- 5.5 Post-diagnostic support for people with young-onset dementia
- 5.6 Post-diagnostic support for young carers

Key recommendation 3: Post-diagnostic support

Post-diagnostic support should incorporate continuity of care, including a 'one-stop' service or single point of contact, a single professional or case manager. This should be a healthcare or social care professional with appropriate skills, knowledge and expertise in dementia (see the Promoting Excellence Framework), working with the GP, to ensure a tailored support package is delivered in a timely manner.

- 6.1 Assessment of distressed behaviours
- 6.2 Comparison with pharmacological interventions
- 6.3 Comparisons with usual care or attention control conditions
- 6.4 Sleep problems
- 6.5 People living with dementia and their carers' perspectives on using technology to support management of dementia

Key recommendation 5: Non-pharmacological approaches for distressed behaviours

For managing distressed behaviour symptoms in people with dementia, tailored activities based on a comprehensive structured assessment may be considered. Activities should be individualised, focus on preserved capabilities and consider previous roles, interests and preferences.

For carers of people with dementia, provision of tailored psychoeducation and skills training may be considered.

Key recommendation 5: Non-pharmacological approaches for distressed behaviours

Components may include:

- problem solving
- identifying triggers
- coping strategies for distressed behaviour
- stress reduction
- cognitive restructuring
- communication skills
- crisis management.

7 Grief and dementia

- 7.1 Anticipatory grief
- 7.2 Pre-death grief in people with dementia
- 7.3 Pre-death grief in the carers of people with dementia
- 7.4 Assessment and measurement of anticipatory and pre-death grief in carers
- 7.5 Pre-death grief and depression in carers
- 7.6 Support and management approaches for carers with pre-death grief

Key recommendation 4: Grief and dementia

Healthcare professionals should be aware that carers of people with dementia may experience pre-death grief from the point of diagnosis and throughout the stages of dementia, and sensitively enquire about these experiences:

worsening pre-death grief as dementia becomes more severe

worsening pre-death grief at transition points, such as when the person with dementia is moved to long-term care.

- 8.1 Assessment of changing and unmet needs
- 8.2 Palliative and end-of-life care approaches
- 8.3 Transitions between care settings
- 8.4 Advance and anticipatory, or future care planning

Key recommendation 6: Changing needs of people with dementia

Changing needs of people with dementia

Healthcare professionals should be aware that existing measures to define end of life in people with dementia based on cognition and ambulatory function may be ineffective and may not recognise the unmet needs at end of life.

Healthcare professionals should focus on the needs of the individual and consider moving away from a focus on defining end of life by disease stage.



Implementation

Work on promotion

Media

Close working with HIS

Dementia Strategy & Workplan

Above all: we need you to drive this



Delivering the SIGN Dementia guideline as a decision support toolkit

Dr Ann Wales, Programme Lead, Knowledge and Decision Support Ann.wales3@nhs.scot

Kirsty Littleallan, Project Support Officer, Right Decision Service team kirsty.littleallan@nhs.scot

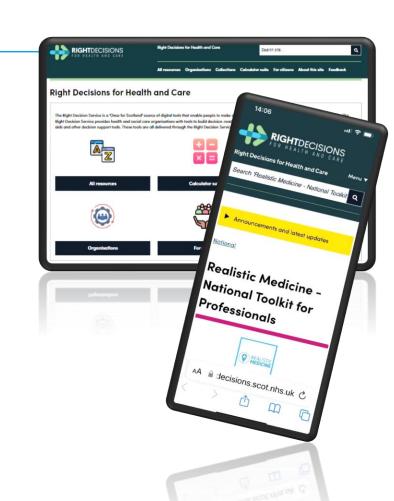






What is the Right Decision Service?

- RDS is a national platform for decision support systems
- A Once for Scotland source of digital tools which brings evidence to the fingertips of practitioners and citizens to support safe, personalised decisions
- Evidence is delivered in decision-ready format through everyday technology – web and mobile apps and electronic care records





National initiative, strong policy mandate



"We will establish a national decision support service by embedding the Right Decision Service across health and social care"

Greater access, better insight,

a strategy for data-driven

improved outcomes:

Scottish Government and COSLA

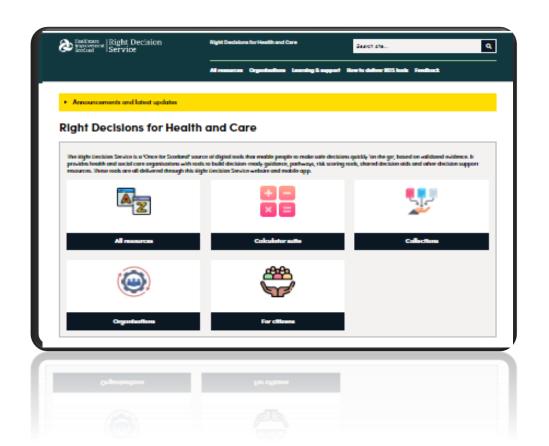
care in the digital age

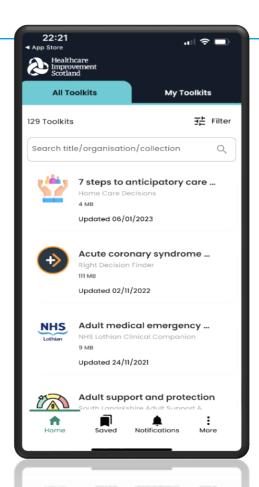
"Establish a national decision support service,"
building on the Right
Decision Service"

"The Right Decision Service is essential to making sure people are accessing the right care at the right time"

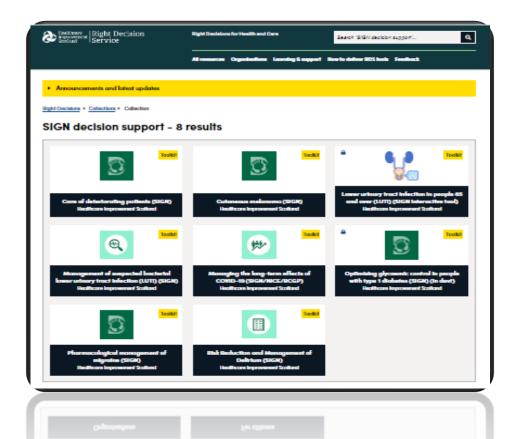


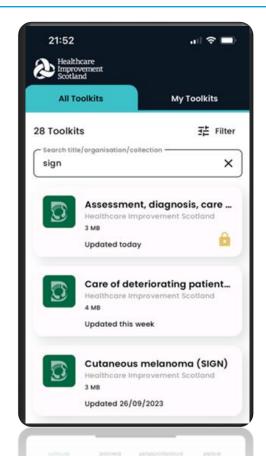
Web and mobile access



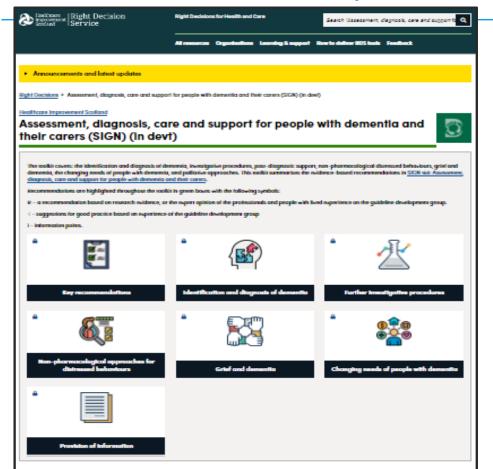


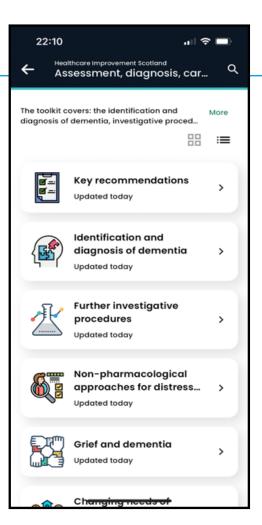
SIGN decision support

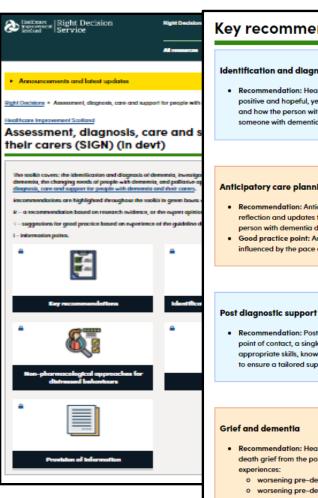




SIGN Dementia toolkit - preview







Key recommendations Identification and diagnosis of dementia

 Recommendation: Healthcare professionals should ensure that the discussion of a diagnosis of dementias positive and hopeful, yet realistic, messages; information on prognosis and sources of support; information and how the person with dementia can continue with their life, maintain their sense of self and accept their

someone with dementia.

Healthcare Improvement | Right Decision | Service

Right Decisions for Health and Care

All resources Organisations L

Anticipatory care planning

- Recommendation: Anticipo reflection and updates to person with dementia dimi
- Good practice point: Antic influenced by the pace of

Announcements and latest updates

Right Decisions > Assessment, diagnosis, care and support for people with dementia and their

Healthcare Improvement Scotland

 Recommendation: Postdia point of contact, a single p appropriate skills, knowled to ensure a tailored suppo

Identification and assessment of suspected dementia

Discussing a diagnosis of dementia

Back to Assessment, diagnosis, care and support for people with dementia and their carers (SI

Identification and diagnosis of dementia

Grief and dementia

- Recommendation: Healthcare professionals should be aware that carers of people with dementia may exp death grief from the point of diagnosis and throughout the stages of dementia, and sensitively enquire about experiences:
 - worsening pre-death grief as dementia becomes more severe
 - worsening pre-death grief at transition points, such as when the person with dementia is moved to lor

Discussing a diagnosis of dementia

Who should be involved and provide a diagnosis of dementia?

When should a diagnosis take place?

How should a diagnosis of dementia be discussed?

GPs or professionals referring a person with suspecied dementia to secondary care (eg a memory clinic) should make it clear to the person that they may have dementia so that they are prepared for a potential diganosis of dementia.

Healthcare professionals should consider offering information or prediagnostic counselling to session that takes place in advance of a meeting to inform a person of a dementia diagnosis) for people with dementia and their carers to:

 discuss and address the beliefs, expeciations and potential misconceptions of people with dementia and their carers help them better absorb and understand the information provided to them.

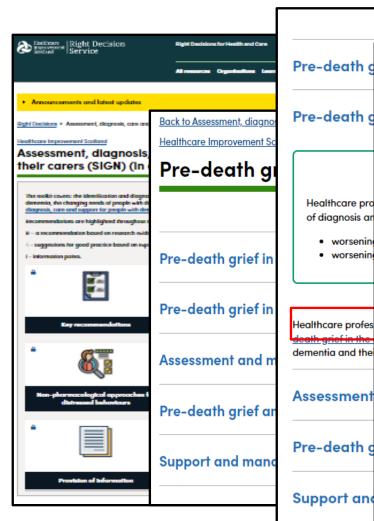
Healthcare professionals should ensure that people with dementia and their carers have access to information before, during and after receiving a diagnosis of dementia. This includes information about memory assessments and the medical, interpersonal and behavioural aspeas of dementia. Written information should be provided at the meeting to discuss diagnosis.

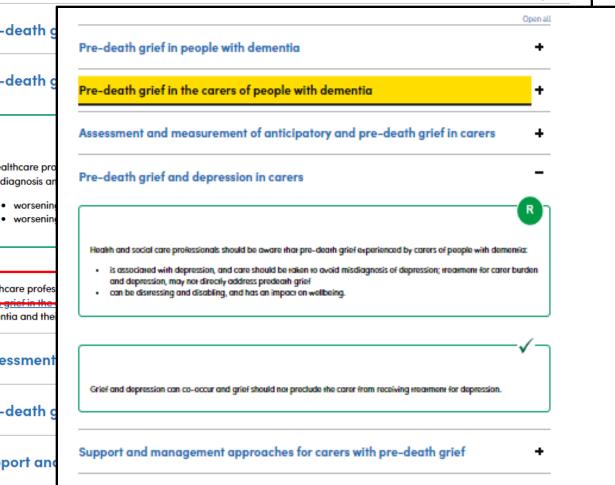
Healthcare professionals providing a diagnosis of dementia should do so in a clear, sensitive and emparteric manner, being aware of the differing communication needs of the person with dementia and their carer(s) and provide the opportunity for

Healthcare professionals should ensure that the discussion of a diagnosis of dementia should include positive and hopeful, yet realistic, messages; information on prognosis and sources of support; information on wellbeing and how the person with dementia can continue with their life, maintain their sense of self and accept their identity as someone with dementia.

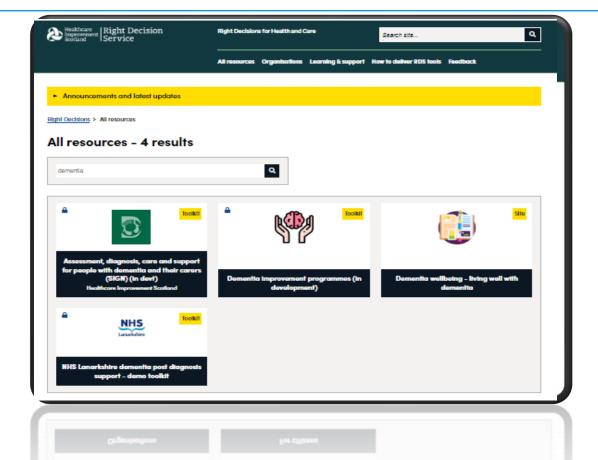
Healthcare professionals should be aware of the increased risk of suicide in people with dementia younger than 65 within 3 months of a diagnosis.

Encourage the person with dementia and their carer(s) to ask questions about the dementia diagnosis and allow sufficient ime for answering, ""checklist for provision of information linked here"





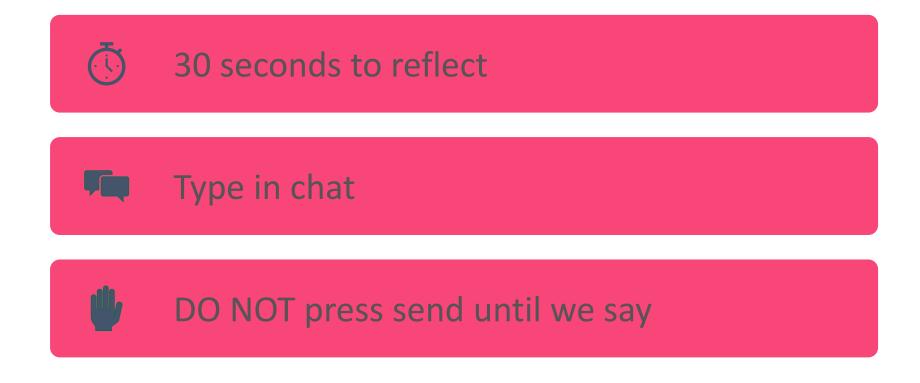
Bringing dementia resources together



Benefits of accessing guidance through the Right Decision Service

- Navigate quickly to specific information needed for decisions at point of care.
- Downloadable mobile access for community settings and hospital sites with poor Internet connectivity.
- Connect to related toolkits dementia improvement, resources for people living with dementia.

Who would use the SIGN dementia decision support toolkit? For what purpose?



Thank you

Web:

http://rightdecisions.scot.nhs.uk

App stores

- Download from links in website footer
- Search for "Right decisions"
- Download "Right decisions for health and care" app

Contact: ann.wales3@nhs.scot







Focus on Dementia

Examples of current work that support putting the guideline into practice





Post-diagnostic Support (PDS)

Julie Miller

Improvement Advisor Healthcare Improvement Scotland



Our PDS work

Community – ongoing and new work to:

improve post-diagnostic support

improve the co-ordination of care and support

Aligns to many recommendations and best practice points in the guideline

Community – PDS Improvement Programme

We are working with 3 teams across Scotland to make improvements to their services.

We selected 3 sites to work with –

- Dundee PDS Team
- Lanarkshire (new) PDS Team
- Edinburgh PDS Teams

All aims fit with SIGN recommendations.

Improving Dementia Post-diagnostic Support - invitation to apply

Our offer of improvement support

We are accepting applications to join the Focus on Dementia Improvement Programme to improve Postdiagnostic Support (PDS). The application process is open from Thursday 18 May until Friday 23 June 2023 a 17:00.

Focus on Dementia are supporting health and social care partnerships (HSCPs) to make improvements to their PDS services. By joining this programme you will have support to:

- understand your system
- · identify improvement priorities and change ideas
- have access to quality improvement expertise and coaching support to implement and evidence changes in practice.

Please see page four of our PDS and Care Co-ordination Change Package for examples of some of the ways (chan ideas) that we can help. Open the change package here https://ihub.scot/news/new-dementia-care-co-ordination-change-package/

The support will include a focus on meeting the new guidelines and aspirations as laid out in the new Dementia SIGI guidelines (due to be published in 2023), the local delivery plan standard for dementia, the standards of care for dementia, and in accordance with the the fourth national dementia strategy (due to be published in 2023).

This improvement work can be small scale (quick wins) or supporting you to set up systems and processes for longe term improvements and helping you to develop a tailored improvement plan that reflects your HSCP's priorities.

The support is available from July 2023 through to June 2024.

Please complete this online form by Friday 23 June 2023, to apply. Successful teams will be notified in the week beginning 10 July 2023.

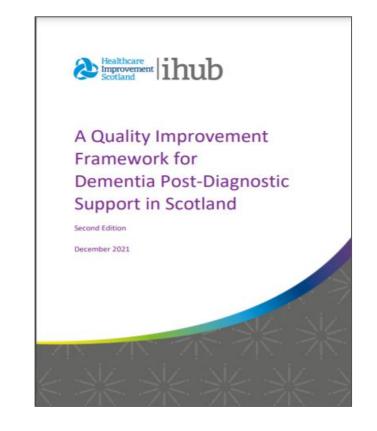
PDS Quality Improvement Framework

- Referenced in the SIGN Guideline
- Self-assessment guide
- Already used by several PDS services
- The new Dementia Strategy promotes its use
- Already supports many SIGN recommendations, good-practice points and information points.

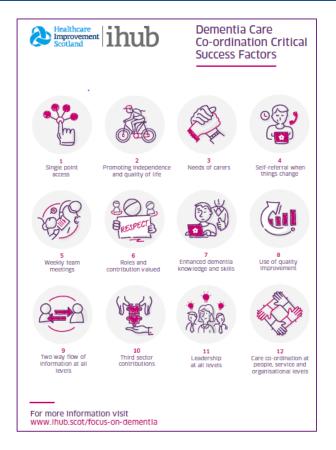


PDS Quality Improvement Framework

- Reviewing the framework
- Taking SIGN recommendations into account e.g. pre-death grief, interlinked needs of carers, physical needs
- Third edition out Autumn/Winter next year.



Care Co-ordination 12 Success Factors – self assessment



Care Co-ordination Critical Success factors			
Critical Success factor			Edday (Company)
Single point access Support from diagnosis to end of life Referral process simple and well known Open referral system Referrals triaged at the point of receipt	Yes	No	Evidence/Comments
Promoting independence and quality of life Maximise community connections and building resilience Support personal centred, outcomesbased, responsive and proportionate to needs. Proactive support around ACP, SDS and PDA etc. Proactive referral to rehab/reablement			
3. Needs of carers • Seen as equal partners • Referral offered to carers support • Carers support plan 4. Self-referral when things change • Written information on how to get back in touch • Person centred mechanism's to keep			
connected e.g. telephone, digital 5. Weekly team meetings • Mechanism in place for MDT/multi-agency sharing of collective expertise			
Roles and contribution valued Organisations and team members know and value each other's role/contribution Roles well bounded			
7. Enhanced dementia knowledge and skills All staff are trained to enhanced level of Promoting Excellence Framework A sustainable framework in place for on-coins staff education and training			

Our Learning System

The Focus on Dementia Portfolio is underpinned by a **National Learning System** which aims to rapidly capture and share learning to support spread at pace and scale. We do this in a number of ways:



Hosting webinars



Sharing evidence summaries



Flexible learning opportunities



Supporting networks



Producing case studies



Develop toolkits and measurement plans





Reducing stress and distress through improved person-centred care planning in hospitals

Marie Innes

Senior Improvement Advisor Healthcare Improvement Scotland



The dementia in hospitals programme

- Scottish Government commission
 Aim improve hospital care for people with dementia
- September 2019 September 2021 (to 2023)
- 3 settings acute, community and specialist dementia units

Programme aim

Hospital care for people with dementia will be informed by a **personalised care plan** which reflects their strengths, needs, wishes and choices.

The person-centred approach will support the prevention and management of stress and distress.

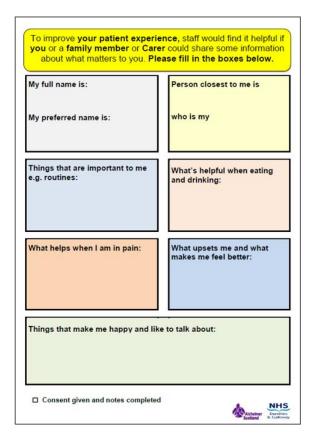
SIGN recommendation: Non-pharmacological approaches for distressed behaviours

For managing distressed behaviour symptoms in people with dementia, tailored activities based on a comprehensive structured assessment may be considered.

Activities should be individualised, focus on preserved capabilities and consider previous roles, interests and preferences.

Activities should be individualised, focus on preserved capabilities and consider previous roles, interests and preferences

- 'Getting to Know Me' processes
- Creating life story books or memory boxes
- Activity planner
- Bedside posters



Next steps

- Supporting Dementia Strategy and SIGN guideline implementation
- Sharing the learning across Scotland
 - Webinars and events like this
 - Website, social media
 - Dementia in hospitals toolkit
 - Linking with other national programmes and partner organisations

Thank you

Please take 2 minutes to complete the short evaluation survey using the link in the chat box

Get connected – join our network! his.focusondementia@nhs.scot

