Improving Dementia Care

www.1000livesplus.wales.nhs.uk
Acknowledgements

This guide has been produced by Professor Bob Woods, with input from Graham Dixon and Mat Phillips. The drivers were produced in conjunction with the Task & Finish Group established by the Welsh Assembly Government to produce a draft National Dementia Plan.

We would particularly like to thank healthcare organisations in Wales and their teams for their work in implementing these interventions and also feeding back lessons and experiences gained as a result.

1000 Lives Plus is run as a collaborative, involving the National Leadership and Innovation Agency for Healthcare, the National Patient Safety Agency, Public Health Wales and the Clinical Governance Support and Development Unit.

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Date of publication

This guide was published in 2010 and will be reviewed in 2012. The latest version will always be available online on the programme’s website:
www.1000livesplus.wales.nhs.uk

The purpose of this guide

This guide has been produced to enable healthcare organisations and their teams to successfully implement a series of interventions to improve the safety and quality of care that their patients receive.

This guide must be read in conjunction with the following:

- Leading the Way to Safety and Quality Improvement
- How to Improve

Further guides are also available to support you in your improvement work:

- How to Use the Extranet
- A Guide to Measuring Mortality
- Improving Clinical Communication using SBAR
- Learning to use Patient Stories
- Using Trigger Tools
- Reducing Patient Identification Errors

These are available from the 1000 Lives Plus office, or online at www.1000livesplus.wales.nhs.uk

We are grateful to The Health Foundation for their support in the production of this guide.
Improving care, delivering quality

The 1000 Lives Campaign has shown what is possible when we are united in the pursuit of a single aim: the avoidance of unnecessary harm for the patients we serve. The enthusiasm, energy and commitment of teams to improve patient safety by following a systematic, evidence-based approach has resulted in many examples of demonstrable safety improvement.

However, as we move forward with 1000 Lives Plus, we know that harm and error continue to be a fact of life and that this applies to health systems across the world. We know that much of this harm is avoidable and that we can make changes that reduce the risk of harm occurring. Safety problems can’t be solved by using the same kind of thinking that created them in the first place. To make the changes we need, we must build on our learning and make the following commitments:

- Acknowledge the scope of the problem and make a clear commitment to change systems.
- Recognise that most harm is caused by bad systems and not bad people.
- Acknowledge that improving patient safety requires everyone on the care team to work in partnership with one another and with patients and families.

The national vision for NHS Wales is to create a world class health service by 2015: one which minimises avoidable death, pain, delays, helplessness and waste. This guide will help you to take a systematic approach and implement practical interventions that can bring that about. The guide is grounded in practical experience and builds on learning from organisations across Wales during the 1000 Lives Campaign and also on the experience of other campaigns and improvement work supported by the Institute for Healthcare Improvement (IHI).
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Introduction

Why focus on dementia?

Public awareness of dementia and media coverage of the condition and its effects has grown dramatically in recent years.

There are now numerous examples of public figures who have developed a dementia, and who have talked publically about their condition (from Ronald Reagan to Terry Pratchett) or whose relatives have talked about the impact on themselves as care-givers (from Iris Murdoch to Margaret Thatcher). There are few families who have not now been touched themselves by this condition, or know others who have.

Dementia is a major concern for health and social care services. It is the single most frequent cause of admission to care homes, and of the need for community care services for older people. Although most people with dementia are in later life, younger people may also be affected, and often receive care in services designed for older people.

The demographics of an ageing population means the number of people with dementia is projected to increase by around a third by 2021. The needs of people with dementia and their supporters already require high levels of health and social care inputs; meeting the projected needs of this rapidly growing group is widely recognised as representing a considerable challenge to governments and to society.

In England, dementia is now seen as an NHS priority area, and earlier in 2009 a National Dementia Strategy was launched. In Wales, the Minister for Health set up a Task and Finish Group to produce a National Dementia Plan for Wales. The draft plan was subject to extensive consultation in the summer of 2009.

Subsequently 4 stakeholder groups with independent chairs produced actions in the following domains:

- Improving service provision through better joint-working across health, social care, the third sector and other agencies;
- Improving early diagnosis and ensuring timely interventions;
- Improving access to information and support for people and ensuring a greater awareness of advocacy services;
- Improving training for those delivering care.

These are available on the Welsh Assembly Government web-site.

This ‘How to Guide’ focuses on specific areas that were developed alongside and in conjunction with the work on the National Dementia Plan for Wales.
**Prevalence**

Dementia is the family name for a number of disorders, all of which have in common a loss of memory and other intellectual functions and a reduction in the person’s ability to care for him/herself, often accompanied by emotional changes and disturbances of behaviour.

There are many types of dementia: the most common are Alzheimer’s disease, vascular dementia and Lewy body dementia. Many older people have mixed dementia, with Alzheimer’s and vascular pathologies evident when the person’s brain is examined at post-mortem.

The UK Dementia Report (2007) provides widely-accepted consensus figures for the incidence and prevalence of dementia. The prevalence of dementia increases with age, with less than 2% of people aged 65-69 having a dementia, compared with over 20% of those aged 80 and over. There are estimated to be 37,000 people with dementia in Wales currently; this is set to increase to almost 50,000 people by the year 2021. Figures on the number of younger people with a dementia in Wales are more difficult to estimate, but a figure of 730 has been suggested (Vetter & Lester, 2008).

**Course and prognosis**

Dementias are typically progressive disorders, although the rate of progression varies greatly between individuals, and is influenced by a variety of factors, including the person’s physical health, medication and age (with younger individuals often showing a more rapid decline). For Alzheimer’s disease, the median survival time after diagnosis is five to six years.

Severity of dementia covers a wide range, from ‘mild’, where the person may have significant memory and new learning problems, but may be well able to communicate and maintain a range of activities; through to ‘severe’, where the person may appear to have little awareness of the environment, and where communication appears limited.

Depression and anxiety symptoms are common, affecting as many as 40% of people with dementia. Challenging behaviour is common, but not universal, and may occur at any stage, but does not necessarily worsen with increased severity of the dementia.

**Economic implications of dementia**

The UK Dementia Report estimates the UK cost of dementia to be over £17 billion per annum. Based on UK figures, the annual direct cost to the NHS in Wales of caring for people with Alzheimer’s disease is estimated by Vetter & Lester (2008) to be at least £80-120 million.

When the costs of informal caring and the costs to all statutory agencies are taken into account, they estimate that the total cost of caring is in the region of £700 million in Wales. It is worth noting that considerable costs are incurred in the general hospital care sector because people with dementia have longer stays in hospital for surgery and medical procedures not directly related to
their dementia. The National Audit Office (2007) identifies this as a key area where savings within the care system could be made by the provision of more appropriate support for people with dementia.

Dementia has an economic impact on families. For younger people with dementia, it is often impossible to carry on working. Employed carers may have difficulty maintaining their employment. Financial costs involved with providing care may include costs associated with a care home placement.

However, the impact on family life and relationships goes far beyond the financial impact. A quarter to a third of carers experience psychological distress, including an increased risk of depression and anxiety. Carers of people with dementia experience greater physical health morbidity. Many carers report experiencing the loss of the relationship with the person with dementia - some liken this to a ‘living bereavement’.

**Where is dementia treated?**

The majority of people with dementia live at home, although nearly two-fifths live in a care home (Vetter and Lester, 2008). This equates to around 14,000 people with dementia living in care homes in Wales. 7,400 people with dementia are estimated to live alone, with 15,600 living with relatives or friends.

Although some surveys have found that as many as three-quarters of residents of non-specialist nursing homes have dementia (Macdonald et al, 2002), the Alzheimer’s Society (2007) suggests more conservatively that two-thirds of older people in care homes have dementia.

What is clear is that many of these people with dementia are cared for in homes not registered to provide care for people with dementia (around a third of care home places are so registered). A number of these care home residents will be amongst the half to two-thirds of people with dementia who never receive a diagnosis.

There have been reports that provision of specialist care home places may be worse in Wales than in England, with Wales having just 14 dedicated care home places per 1,000 of the population aged 75 and over, compared with 20 or more in most other UK regions. Vetter & Lester (2008) suggest that as many as a third of care home residents with dementia receive anti-psychotic medication.

There is wide variation across Wales in NHS provision for people with dementia. Most areas will have acute in-patient assessment beds; some have day hospital provision, for assessment and treatment; some have continuing assessment beds, where length of stay may be extended and end-of-life care provided.

**Principles for treatment**

The NICE-SCIE Guideline provides a detailed account of the evidence-based approach to the assessment and management of dementia. It emphasises a person-centred approach, where the person with dementia is valued as an individual, whose perspective must be central to any care-plan or intervention, and for whom maintaining social relationships and social inclusion will form a major contribution to quality of life.
The crucial role of family care-givers and other supporters is emphasised, with the implication that care-plans and interventions must address their needs, alongside those of the person with dementia.

Maintaining the quality of life of the person with dementia and carer is the key objective. Recognising, and treating, symptoms of anxiety and depression for both person with dementia and carer, contributes to this objective.

The majority of people with dementia would prefer to stay at home, and so efforts to maintain the person there are highly significant. This may require offering the carer a range of supports - emotional and practical, including short breaks - to assist in providing the extended input that may be required. Challenging behaviour reduces quality of life for people with dementia and for carers, and is often the focus of interventions and the trigger for more intensive supports, including hospital and care home admissions.

In an attempt to manage challenging behaviour, anti-psychotic medication may be prescribed, although the prolonged use of such medication is associated with reduced quality of life and increased risk of death. Alternative approaches are not well-developed or widely accessible.

People with dementia continue to have a variety of needs beyond those simply attributable to the dementia. Maintaining the person’s physical health is essential, but this can prove challenging when an admission to a general hospital medical or surgical ward is indicated, not least because of the vulnerability of the person with dementia to additional delirium superimposed on their existing cognitive impairment.

Timely diagnosis is seen as important in helping the person and supporters to be able to make sense of changes being experienced, and to make adjustments and plans for the future. In the UK, it is recommended that diagnosis be made by specialist services. These are provided by memory clinics or memory assessment services forming part of a CMHT for older people.

Alzheimer’s Europe (2005) suggest that the time between symptoms being noticed and a diagnosis being given is longer in the UK (32 months) than in many other European countries (Spain 18 months, Italy 14 months, Germany 10 months). This may be related to the differential availability of the medications currently licensed for Alzheimer’s disease (the acetylcholinesterase inhibitors - AchEIs). Current NICE Guidance stipulates (likely to be revised in 2011) that they should only be offered in the moderate stages of dementia, whereas practice in most other countries is to offer them early, to prevent and slow down further decline.

**Preventing harm**

The five areas covered by the dementia targets were selected through a process of consultation with people with dementia, carers and practitioners in 2009, drawing also on recommendations from the NICE-SCIE Guidelines.

Each area is associated with the risk of harm to people with dementia and/or their carers. The use of anti-psychotic medication (Driver 3) is associated with an increased risk of death and stroke. People with dementia in general hospitals
(Driver 2) remain in hospital for longer than people without dementia undergoing the same procedure, and, as with those in NHS dementia units (Driver 5) are exposed to the risks associated with poor quality care. A significant proportion of carers experience psychological distress, depression and anxiety related to their care-giving (Driver 4). Failure to achieve timely diagnosis (Driver 1) restricts opportunities for forward planning and for timely interventions, and may be associated with worse outcomes (Rait et al., 2010).

References

Improving Dementia Care

Driver Diagram

**Content Area**
- To improve the quality of life and care for people with dementia and their care givers
- To improve memory assessment services
- To improve care on general hospital wards
- To improve community care (including in care homes)
- To increase support for care givers
- To improve quality of care in NHS dementia in-patient units

**Drivers**
- First point of contact - reduce time between onset of symptoms & diagnosis being communicated
- Rapid referral from primary care to memory assessment service.
- Multi-disciplinary Assessment care bundle
- Feedback, interventions and signposting care bundle
- Identify on admission
- Follow dementia pathway when identified
- Improved care planning
- Reduced inappropriate use of anti-psychotic medications in accordance with NICE/SCIE guidelines. Use alternative approaches to anti-psychotics where possible.
- Carers involved in care-planning
- Educational and therapeutic interventions and training for caregivers
- Better admission procedures
- Involve families
- Use appropriate interventions
1. Memory Assessment Services

These show the detailed elements of the interventions listed on the main driver diagram

To improve memory assessment services
- First point of contact - reduce time between onset of symptoms & diagnosis being communicated

Drivers
- Rapid referral from primary care to memory assessment service.
- Multi-disciplinary Assessment care bundle
  - Pre-diagnostic assessment counselling
  - Neuropsychological assessment
  - Brain scan
  - Physical health screen

Interventions
- Feedback, interventions and signposting care bundle
  - Within agreed timeframe from initial referral, provide verbal and written feedback on diagnosis to include relevant information, guidance re future planning, appropriate interventions, need for repeat assessments.
  - Discuss potential interventions on offer to promote adjustment and adaptation and promote social networks
  - If dementia, refer to Alzheimer’s Society and carers’ organisations
Getting Started

**Have you set up your team?**
You need to consider three different dimensions:

- Organisational level leadership
- Clinical or technical expertise
- Frontline leadership and team membership

*See the ‘Leading the Way to Safety and Quality Improvement’ How to Guide; and Appendix E for further information.*

**Do you know how you will measure outcomes?**
For this content area, the outcomes being pursued are listed below. Not all can be readily measured directly immediately, and process measures (see Appendix C) have been selected to monitor progress towards achieving these outcomes.

**Driver 1:** Rationale - Timely diagnoses allowing (i) earlier interventions, planning and decision-making for the future and (ii) reduced uncertainty for people with suspected dementia and supporters

- Reduced time between onset of symptoms & diagnosis being communicated
- Percentage of patients referred with suspected dementia from primary care to a memory assessment service, who receive an assessment and feedback on the assessment, within a specified time period (reflecting improvement on baseline)

**Driver 2:** Rationale: Improved quality of general hospital care for people with dementia

- Reduced length of stay for people with dementia in general hospitals
- Increased percentage of supporters satisfied with care received

**Driver 3:** Rationale - Increased quality of life for people with dementia

- Reduction in percentage of people with diagnosis of dementia receiving anti-psychotic medications and reduction in duration:
  - In care homes (includes nursing and residential places)
  - In NHS dementia units
  - Living in the community
  - In general hospitals
Driver 4: Rationale - Improved quality of life for carers of people with dementia

- Reduced distress in family carers of people with dementia

Driver 5: Rationale - Improved quality of care for people with dementia in NHS dementia care units

- Increased percentage of supporters satisfied with care received.
- Improved quality of care demonstrated by use of an accredited observational tool

Do you and your team understand how to apply the Model for Improvement?

The Model for Improvement is a fundamental building block for change and you need to understand how to use it to test, implement and spread the interventions in this guide.

See the ‘How to Improve’ Tools for Improvement guide and Appendix E for further information.

How are you going to measure process reliability?

In order to improve outcomes for your patients you need to demonstrate you are following the interventions contained in this guide. You need to do this by using the process measures in this guide, some of which involve audits of current practice.

See the ‘How to Improve’ Tools for Improvement guide and Appendix C for a summary of all process measures.

How will you share your learning?

Contact 1000 Lives Plus for details of mini-collaboratives and other ways to share your learning and to learn about the progress of other teams.
Drivers and Interventions

Improving memory assessment services

This section details the interventions highlighted in the driver diagram which evidence has shown to be effective in this content area. You should use the Model for Improvement to test, implement and spread each intervention, using the listed process to monitor progress.

Driver: First point of contact - reduce time between onset of symptoms & diagnosis being communicated.

The proposed benefits of timely diagnoses include:

- Reduced uncertainty for people with suspected dementia and their supporters
- Increased opportunities for planning and decision-making for the future, including Lasting Powers of Attorney, financial planning and discussion of preferences regarding housing and care
- Earlier interventions, facilitating adjustment and coping

Banerjee and Wittenberg (2009) suggest that there are feasible benefits for quality of life and ultimately more efficient use of resources from this approach. Koch & Iliffe (2010) highlight some of the barriers to achieving timely diagnosis, including patient factors (delay in coming forward), GP factors (e.g. lack of time, uncertainty about the diagnosis) and system characteristics (e.g. difficulty in accessing specialist services).

Context

This driver applies to memory assessment services, established to provide specialist non-urgent assessments leading to diagnosis and interventions for people with suspected dementia.

Interventions

Rapid referral from primary care to memory assessment service.

GPs and primary care teams need to be alert to memory problems and aware of referral pathway. NICE-SCIE Guidelines recommend that diagnostic assessment be carried out by a specialist memory assessment service.
**Measures:**

For this intervention, use the following process measures:

- Time between first onset of symptoms reported by patient and / or supporters and referral to memory assessment service.

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**Applying the Model for Improvement**

**Aim:** To ensure that primary care teams are aware of the referral pathway

**Improvement monitoring:** Examine referral rates from primary care teams across the area, standardised by the population aged 65 and over (standardised rate = number of referrals received divided by number aged 65 and over on practice list).

**Change required:** Use PDSA cycles to develop and test methods of informing practices which have standardised referral rates in the lowest 25% in relation to recognition of memory difficulties and the referral pathway.

**Assessment tools:**

The Alzheimer’s Society produces a range of resources for primary care teams, from posters to CD-ROMS. See:

www.alzheimers.org.uk/site/scripts/documents_info.php?categoryId=200306&documentId=367

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**Examples of local practice**

- Training for primary care teams including ‘roadshows’
- Information packs for primary care, social services and voluntary sector regarding the Memory Assessment Service

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**Top Tips**

- A single point of access provides the simplest referral pathway, and allows urgent referrals to be dealt with immediately, whilst most cases of suspected dementia can be seen on a more measured basis.
- Make sure dementia features regularly in primary care training events
- Ensure that if screening tools are used in primary care, the likelihood of missing significant memory problems in people with high educational attainment is emphasised
Ensure that primary care teams are aware of the range of potential interventions that may be available, including, but not limited to, medication.

Encourage public awareness locally, with events and publicity that diminish the stigma associated with dementia.

Many people with dementia and their families are prepared to consider participating in relevant research projects in the period after a diagnosis has been made. Even if there are no local projects recruiting, patients and carers can join the NEURODEM Cymru database of potential research participants, to receive regular newsletters and details of new projects: http://tinyurl.com/2525zbc

**Patient engagement**

If the memory assessment service does not have a self-referral facility, provide good, clear written information, for those who are concerned regarding their memory, as to how to go about receiving an assessment. This could be produced jointly with the local Alzheimer’s Society, as an add-in to their ‘Concerned about your memory’ leaflet.

http://tinyurl.com/39hpkjq

**Multi-disciplinary Assessment**

This section comprises a ‘care bundle’ made up of key features of the non-urgent assessment of a person with suspected dementia. It is NOT intended to be a comprehensive list, which would include, for example, assessment of functional abilities, social support and mood. The features included are those recommended by the NICE-SCIE guidelines that have proved more difficult for all memory assessment services to provide.

**Pre-diagnostic assessment counselling**

It is good practice to ensure that the person referred understands the assessment process and the potential implications.
Neuropsychological assessment

NICE-SCIE recommends a neuropsychological assessment in all cases of suspected dementia. The MMSE is not adequate as a neuropsychological assessment. The assessment should include evaluation of memory, attention, language, praxis, executive function and perception.

More detailed assessment may be required where the person was either of previously high intellectual level, or has had limited educational attainment. Language preference and the effects of assessment in a second language must be carefully considered.

Brain scan

NICE-SCIE recommends a brain scan (preferably MRI) in order to assist with diagnosis of sub-type of dementia. This should be considered in every case, but a decision may be made that it is inappropriate where, for example, the person is physically frail. This decision should be discussed with the patient and documented.

Physical health screen

The diagnostic process must exclude potential physical health difficulties that may lead to cognitive impairment. With an agreed protocol this may be undertaken by the GP.

Measure:

For this intervention, use the following process measure:

- % compliance with the care bundle

Applying the Model for Improvement

Aim: To ensure that a timely assessment of appropriate rigour is carried out in each case.

Improvement monitoring: Identify components of the assessment process that are difficult to provide, or which lead to delays in the assessment process.

Change required: Establish a work group from the memory assessment service to work on maximising the effective use of assessment resources, and identify any gaps in provision. Use PDSA cycles to find ways of achieving the required assessment components in an acceptable time-scale.

Assessment tools:

An audit checklist is available (Appendix A)
**Examples of local practice**

- All patients referred to one service are seen initially by a nurse, who explains what the assessment will entail, and ensures the person understands the nature of the assessment and its implications. The person’s preferences for receiving the feedback (e.g. alone / with another / only to a relative) are also recorded. Carrying out this visit at home provides an excellent opportunity to evaluate the functional impact of the problems and available social support networks.

- In a service where medical input was limited, a shared care protocol was agreed with primary care teams, where key physical investigations, including blood tests, were carried out at the time of referral. Where this was not carried out for any reason, the GP was reminded of the tests required.

- In a service where clinical psychology input is limited, a clinical psychologist works with the team to identify those people for whom a full neuropsychological assessment will add to the diagnostic assessment, and oversees the interpretation of a brief neuropsychological profile (the ACE-R), administered by other members of the team. In another team, an Assistant Psychologist, under the supervision of a clinical psychologist, carries out a proportion of the assessments.

- A Welsh-language version of a standard neuropsychological profile is being developed and validated in one service.
Top Tips

- Missed appointments can significantly prolong the assessment process. A telephone call the day before the appointment, or, with the person’s agreement, notifying a relative of the appointment can reduce the rate of DNAs.

- A structured proforma for the initial assessment can ensure that all relevant information is collected, including the impact on relatives and other supporters, and the person’s own perspective on their difficulties.

Patient engagement

An information leaflet about the service will assist the person and their supporters in knowing what to expect and who to contact with any queries.

Feedback, interventions and signposting

*Within agreed timeframe from initial referral, provide verbal and written feedback on diagnosis to include relevant information, guidance re future planning, appropriate interventions, need for repeat assessments.*

Clear feedback, in a timely fashion, is needed to provide the benefits of enabling planning for the future and reducing uncertainty. Assessments for suspected dementia are not always immediately conclusive, but feedback should be given as soon as the assessment is complete, even if it is inconclusive and further follow up will be needed. Although sometimes described as ‘sharing the diagnosis’ the discussion needs to be much broader than this.

*Discuss potential interventions on offer to promote adjustment and adaptation and promote social networks*

The availability of medications for dementia acted as an impetus for the development of memory assessment services, but there are many people with mild dementia for whom medication is not appropriate, and a range of interventions should be available and offered to all people newly diagnosed with dementia. NICE-SCIE recommends, for example, that all people with mild to moderate dementia should be offered the opportunity to take part in cognitive stimulation groups, irrespective of whether they are receiving medication.

*If dementia, refer to Alzheimer’s Society and carers’ organisations*

Third sector organisations are well placed to provide support for those with mild dementia, encouraging social inclusion and offering information and education about the condition. It is good practice to offer, with the person’s permission, to make the referral, rather than simply to leave it to the individual to make contact.
Measure:

For this intervention, use the following process measures:

- Median time from referral by GP, social worker or other primary care worker to feedback interview.
- % compliance with the three interventions in this care bundle

Applying the model for improvement

Aim: Increase the proportion of patients referred with suspected dementia from primary care to a memory assessment service, who receive an assessment and feedback on the assessment within a specified time period, reflecting an improvement on baseline.

Improvement monitoring: Collect and review the key process measure of median time between referral and feedback session.

Change required: Establish a work group to identify the limiting steps in the assessment pathway and use PDSA cycles to develop ways of short-circuiting delays whilst maintaining the quality and integrity of the assessment. Seek to achieve improvement from baseline measures.

Assessment tools

See Audit checklist in Appendix A.

Examples of local practice

- One service has produced and collated a set of information materials, from the Alzheimer’s Society and other local sources, so that the person has a pack tailored to their own condition to take away from the feedback session.
- One service offers regular support groups for people newly diagnosed with dementia to attend with their relatives.
- One service offers regular reviews to people who have an initial diagnosis of Mild Cognitive Impairment, in view of their increased risk of developing dementia at some future point.
Top Tips

- Consider signing up for the Royal College of Psychiatrists Memory Services National Accreditation Programme, or appraise your own service against the published quality standards: www.rcpsych.ac.uk/quality/quality,accreditationaudit/memoryservicesaccreditation.aspx

- Invite the local Alzheimer’s Society to meet regularly with the team, and provide up-to-date information about local resources such as Alzheimer’s Cafés. Explore joint working on intervention strategies.

- Have a standard form for providing information on the assessment to the person, with the individual details added in, for the person to take away. Keep a copy for the file, so there is clarity as to what exactly the person has been told.

- Have training sessions on providing diagnostic feedback, to include:
  - Where possible, have two members of the team in every feedback session
  - Starting with the person’s understanding of their condition, and building on this. (A diagram of the brain is often helpful to have to hand.)
  - Avoiding euphemisms.
  - Giving a clear diagnosis, including the suspected type of dementia
  - Directing the person and supporters to where they can find additional information on the condition if they wish to do so.

- Providing feedback is not a one-off event; offer a session a week or so after the initial feedback session to respond to any queries that have arisen subsequently.

Patient engagement

Regularly invite feedback on the memory assessment service through a structured feedback form.
2. General Hospital Wards

These show the detailed elements of the interventions listed on the main driver diagram.

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<th>Content Area</th>
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<tr>
<td>Identify on admission</td>
<td>Where no previous history of dementia: Check history with family / other supporters</td>
<td>Identify on day of admission if person already has diagnosis of dementia. If so, liaise immediately regarding care needs in relation to dementia (including medication) with family and professional carers, and commence discharge planning.</td>
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<tr>
<td>Follow dementia pathway when identified</td>
<td>Assess for delirium and ensure appropriate treatment</td>
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<tr>
<td>Improved care planning</td>
<td>Seek advice from Liaison service for Older Adults with Mental Health problems, especially where additional needs identified from risk assessment in relation to challenging behaviour.</td>
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<tr>
<td>To improve care on general hospital wards (and reduce length of stay)</td>
<td>Assess environmental needs - safety, stimulation, need for single room etc</td>
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<td></td>
<td>Assess needs for assistance and maintaining skills with meals, toileting, self care etc. and ensure built into care plan and care provided accordingly.</td>
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<td></td>
<td>Review all psychotropic medication on admission. Any psychotropic medication to start with low dose, be time-limited and aimed at specific, recorded and quantified target symptoms and reviewed at least weekly.</td>
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<td>Assess for capacity for major decisions, and where person lacks capacity, follow ‘best interests’ process</td>
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<td></td>
<td>Carers to be involved in care-planning for the person in relation to discharge planning.</td>
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<tr>
<td></td>
<td>If the patient has a diagnosis of dementia when being discharged: all carers offered Carers Assessment.</td>
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Improved quality of general hospital care for people with dementia and reduced length of stay

Care of people with dementia in general hospitals has been widely recognised as falling short, overall, of acceptable standards. This has been extensively documented in the 2009 Alzheimer’s Society report ‘Counting the cost: caring for people with dementia on hospital wards’.

Campaigns to enhance dignity in care settings also identify the general hospital setting where people with dementia are at particular risk, for example, in not being offered assistance required with food and drink (Age Concern, Hungry to be Heard, 2006).

People with dementia remain in hospital for longer than people without dementia who are admitted for the same treatment or procedure, and it has been suggested that at any one time the majority of people with dementia in acute general hospital beds no longer require acute hospital care. Many admissions arise from pneumonia or urinary tract infections, a number of which could, it has been suggested, been prevented or treated in the community.

These are key safety issues, with people with dementia having longer exposure to the risks of being in an acute hospital ward, and being dislocated from their familiar environment. The need for care home placement is often then identified during an acute hospital admission, leading to delays in discharge whilst a suitable placement is arranged.

Prevention of acute hospital admissions might well allow people with dementia to stay at home for longer. This is an area where more effective care of people with dementia could reduce the costs of care, given the premium cost of acute hospital beds.

However, general hospitals have focused on the care of people with acute illnesses, and responding to the challenges of co-morbid dementia has not been seen as a central component of their service. General nurses feel their skills reside in acute physical conditions, and may have received little training in care of people with dementia.

**Context**

People with dementia, or suspected of having dementia, admitted to general hospital wards.
Driver: Identify on admission

Persons diagnosed with dementia need to be identified at an early stage and fast tracked through the hospital system allowing quicker provision of complex packages of care and a safe return home.

Interventions

*Identify on day of admission if person already has diagnosis of dementia. If so, liaise immediately regarding care needs in relation to dementia (including medication) with family and professional carers, and commence discharge planning.*

If a person admitted to a general hospital ward already has a diagnosis of dementia, this needs to be flagged up immediately, through an admission checklist, and contact with the person’s GP and next of kin. Liaison then needs to be established with those already involved with the care of the person with dementia.

*Where there is no previous history of dementia, check history with family / other carers or people offering support*

If the person appears on admission to have cognitive impairment, it is essential to immediately check with those who know the person well how long the impaired cognitive functioning has been present. If this is a few days or weeks, then assessment for delirium is essential. If longer, then liaise with the Liaison service for Older People with Mental Health Problems, in relation to a possible diagnostic assessment.

*Assess for delirium and ensure appropriate treatment*

If the person appears disorientated, has difficulty maintaining attention and shows disorganised thinking or incoherent speech, and there is a history of this impairment developing recently, or becoming much worse recently (where the person has a diagnosis of dementia or long-standing cognitive impairment), follow a delirium assessment pathway (NICE guideline CG103, 2010).

This should aim to identify and treat underlying medical conditions, such as infections, or drug reactions.
**Measures:**
For this intervention, use the following process measures:

- Proportion of patients admitted (as percentage of at risk group i.e. over 65s) where admission checklist indicates that information regarding any dementia diagnosis was sought.
- Proportion of patients with delirium where delirium assessment pathway was followed.

**Applying the model for improvement**

**Aim:** To ensure that people who have dementia and delirium in general hospital settings are correctly identified.

Improvement monitoring: Audit of assessment checklists; Relatives survey.

**Change required:** Member of the nursing team will complete hospital admission checklist within 24 hours of admission, completing all domains allowing provision of baseline data relating to current and previous function. This should include seeking information from relatives or other informants where needed.

Using PDSA cycles, evaluate whether the format of the checklist requires changing and whether the information relating to a diagnosis should be kept separate allowing easy identification if the patient is transferred to another ward. Questions to ask regularly include: Is the checklist compliant with the hospital’s delirium pathway? Did the process fit into the normal working practice of nurses?

**Assessment tools**

Simple tools for assessing delirium are available e.g. the Confusion Assessment Method (Young & Inouye, 2007, BMJ, 334, 842-6).


Top Tips

- Ensure all domains within the admission checklist are completed.
- Ensure routine blood screening is completed on the day of admission.
- Ensure all screening test results are reviewed by the medical team when test results are available, so effective intervention can take place as soon as possible.
- During conversation with family members identify any likes/dislikes that the patient may have.
- Obtain a brief social history to provide you with information to engage in meaningful communication with the patient.
- Use the ‘This is me’ leaflet (published by the Alzheimer’s Society / RCN) - a simple tool enabling the person with dementia to be seen and valued as an individual.

Patient engagement

Patients should be encouraged to participate in the checklist completion regardless of their cognitive ability. By following a person-centred approach to care, the patient is placed at the centre of the care planning and discharge process allowing us to discover more about them as a person.
Driver: Follow dementia pathway

When a person with dementia becomes physically ill they do not always fit into the established systems and pathways. They can require longer periods of rehabilitation and in some cases there will be delays in discharge whilst awaiting care home placement.

Interventions

*Seek advice from Liaison service for Older Adults with Mental Health problems, especially where additional needs identified from risk assessment in relation to challenging behaviour.*

The NSF for Older People (2006) specified that there should be such a service in every part of Wales, although they vary in size and multi-disciplinary composition. They have a key role in supporting staff on general hospital wards in the care of people with dementia, and will have expertise in managing difficult behaviour.

Assess environmental needs - e.g. safety, stimulation, need for single room

People with dementia are often highly responsive to the care environment, and may be less adaptable than a person without dementia. A calm, relaxing environment with multiple cues supporting orientation will be helpful.

Highly polished floors and perceived restrictions on movement may lead to increased risk of falls. Some patients may benefit from having a single room; others may need the reassurance of being able to see others. The NICE delirium guidelines (2010) suggest the following considerations for people with delirium, which are also a good guide for dementia:

- Provide appropriate lighting and clear signage. A clock (consider providing a 24-hour clock in critical care) and a calendar should also be easily visible to the person at risk.
- Re-orientate the person by explaining where they are, who they are, and your role.
- Introduce cognitively stimulating activities (for example, reminiscence).
- Facilitate regular visits from family and friends.

Assess needs for assistance and maintaining skills, e.g. with meals, toileting, self care, and build into care plan accordingly.

A person-centred approach is required, with an individual profile and care plan being drawn up, setting out clearly the areas where the person with dementia may require assistance, and taking into account the person’s preferences.
**Review all psychotropic medication on admission.**

If psychotropic medication is needed, start with low, time-limited doses, aimed at specific, recorded and quantified target symptoms and reviewed at least weekly.

If the person is already on psychotropic medication (e.g. anti-depressants, sleeping tablets, anxiety reducing medication, anti-psychotic medication), this should be reviewed on admission, in consultation with the Liaison team for Older Adults with Mental Health problems, as should the introduction of any new medications of this type.

The review is an opportunity to rationalise drug therapy, identify drug-related problems and discuss any issues regarding compliance. Anti-psychotic medication is thought to be over-used in general hospitals with people with dementia (Alzheimer’s Society, 2009), and the considerations set out in detail in relation to the reduction of anti-psychotic medication in section 3 also apply in the general hospital context, with the exception that reviews must be carried out within days, rather than months.

**Measure:**

For this intervention, use the following process measures:

- Number of patients following agreed dementia care pathway (as percentage of at risk group i.e. over 65s)
- Proportion of people with dementia on anti-psychotic medication
- Relatives’ satisfaction with care survey

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**Applying the model for improvement**

**Aim:** To ensure that people with dementia admitted to general hospital wards follow an agreed dementia care pathway

**Improvement monitoring:** Audit of referrals to Liaison team for Older People with Mental Health problems; audit of care plans of people with dementia; relative’s satisfaction with care survey.

**Change required:** A fundamental change required is agreement on a dementia care pathway for the general hospital, operationalising the interventions in this care bundle. Environmental modifications and staff training and development may be required to support the pathway. Agreement on the role of the liaison service will need to be reached. Ward level work groups, following PDSA cycles will then be needed to ensure the day-to-day implementation of the interventions.
Assessment tools

An audit tool / spreadsheet is available from the 1000 Lives Plus web-site:
www.wales.nhs.uk/sites3/page.cfm?orgid=781&pid=48639#Dementia

**Examples of Local Practice**

- A recently expanded liaison service has established regular training sessions for ward staff on dementia, and is receiving regular referrals enabling it to support staff e.g. on medications management, providing advice and support before prescribing is initiated.

- A multi-disciplinary group meets regularly in another hospital and has organised training sessions for ward staff jointly on dementia and learning disabilities.
Top Tips

- Use the ‘This is me’ leaflet (published by the Alzheimer’s Society / RCN) - a simple tool enabling the person with dementia to be seen and valued as an individual.

- During conversation with family members identify any likes/dislikes and all care needs that the patient may have.

- Obtain a brief care needs history to provide you with information to complete a meaningful care plan.

- Carry out nutritional screening for all people with dementia on admission, to ensure that those at risk are identified and appropriate action taken, with input from dietician.

- Allow carers, family and friends to assist at meal-times if they wish.

- Ensure full medications history is taken at the point of admission.

- Make contact with GP, family and/or carers to establish if medications have recently been changed and/or amended.

- One of the main goals of treatment is not only to alleviate symptoms, but also prevent them from recurring. Therefore adhere to a schedule in administering medications and avoid an “as needed” approach to pharmacotherapy.

- Whenever feasible, choose one drug over many.

- Before initiating therapy, define the short term and long term goals of treatment.

- Can prescribing of psychotropic medications be avoided by initiating a behavioural management approach to care i.e.: changes to environment, supportive approaches, Orientation techniques?

- Start low, go slow and plan the duration of drug treatment.

- Monitor patient on a regular basis for therapeutic and adverse effects. Carefully evaluate the effect of treatment on the overall quality of life and function of the patient, not just the target syndrome or symptoms.

- Always document the outcomes of treatment.

Patient engagement

Prior to psychotropic medications being prescribed, issues relating to adverse side effects and duration of treatment should be discussed with the patient and/or family and carers to seek their views and discuss the rationale for prescribing.
Driver: Improved care planning

Interventions

Assess for capacity for major decisions, and where person lacks capacity, follow ‘best interests’ process

Major, life-changing decisions regarding the person with dementia are frequently made in acute hospitals. The Alzheimer's Society (2009) survey suggested that a third of people with dementia who go into hospital from their own home are discharged into a care home.

Discharge to the person’s own home becomes increasingly unlikely the longer the person remains in hospital. The Mental Capacity Act provides the legal framework for decision making for all health and social care staff, in relation to people who may lack capacity. Capacity is assumed, until an assessment indicates that the person lacks capacity in relation to a particular decision.

If the person is likely to regain capacity e.g. after recovery from acute physical illness, the decision should be delayed if possible. The person must be as fully involved with the decision as possible, even if they lack capacity. The needs of the person for an independent advocate should be considered. All assessments of capacity and decisions made should be fully documented.

Carers to be involved in care-planning for the person in relation to discharge planning

This involvement is needed from the time of admission, when the carer can provide much useful information to the hospital team. Sharing of information needs to be two-way, with communication with the person with dementia and the carer before decisions are taken.

At discharge, the carer should be satisfied with all the arrangements that have been put in place, and feel able to take on or continue the role of carer.

If the patient has a diagnosis of dementia when being discharged: all carers offered Carers Assessment

Carers have a right to an assessment of their needs. Discharge from hospital provides a good opportunity to offer this to those who will be providing care (see also section 4, on increasing support for caregivers).

Measure:

For this intervention, use the following process measures:

- Relatives’ satisfaction with care survey
Applying the model for improvement

Aim: To ensure that the person with dementia is discharged as soon as their physical health needs allow, to their usual place of residence wherever possible.

Improvement monitoring: Audit of discharge plans to monitor carers’ involvement, offer of Carers’ Assessment and documentation of decision making.

Change required: Implementing this care bundle requires recognition of the key role played by carers and of the difficulty of assessing care needs of people with dementia in a general hospital environment.

Speedy, planned return to a familiar environment, perhaps with enhanced support, will allow life-changing decisions to be made in a planned, considered manner, rather than under the pressure of occupying an expensive general hospital bed.

Joint agency working groups will be needed to address these issues, and may highlight further training needs. Carer involvement in training sessions, and their feedback through the relatives’ surveys can be influential.

Assessment tools
Relatives’ satisfaction with care survey form available from: www.wales.nhs.uk/sites3/page.cfm?orgid=781&pid=48639#Dementia

Examples of local practice
- Relatives’ satisfaction with care survey has been piloted in one hospital, and a reasonable response rate obtained.
Top Tips

- In relation to decision-making, does the person have all the relevant information needed to make the decision? If there is a choice, has information been given on the alternatives.

- Could the information be explained or presented in a way that is easier for the person to understand? Help should be given to communicate information wherever necessary.

- Provide the carer with sufficient information and explanation of the nature of the patient’s illness/condition or disability to enable them to care for the patient on discharge.

- Provide the carer with clear and detailed information, support and training where necessary regarding the following:
  - Follow up appointments/visits
  - Personal care procedures e.g. care of wound/catheter/continence advice
  - Dietary arrangements
  - Equipment and aids
  - Information regarding a care package
  - Information for community nursing service
  - Supply of medication and administration techniques
  - Provide the carer with a copy of the final discharge plan with patient’s agreement.

- Provide Carer with details of a named contact and telephone number to use following discharge in case any difficulties arise post-discharge (e.g. Community Nurse, Social Worker, GP)

- In circumstances where patients refuse permission to allow the carer to be involved in decisions about their future care, carers should be informed of this, and their right to a Carer’s Assessment reinforced. There may be occasions where a carer’s needs or wishes conflict with the patient’s aspirations and in these situations staff teams should review the care plan and endeavour to find a realistic solution for all concerned.

Patient engagement

Engaging the patient and carer fully is central to this intervention.
3. Community mental health services for people with dementia including those resident in care homes

These show the detailed elements of the interventions listed on the main driver diagram

- **Content Area**: To improve community care (including in care homes)
- **Drivers**: Appropriate use of anti-psychotic medications in accordance with NICE/SCIE guidelines, and avoidance where possible
- **Interventions**:
  - Full discussion with patient and / or carers about possible benefits and risks of treatment.
  - Assess for capacity and where person with dementia lacks capacity, follow ‘best interests’ process regarding use of anti-psychotics
  - Anti-psychotic medication to be used with people with dementia after other approaches have been tried (see NICE-SCIE, 2007), unless person at immediate risk of harming self or others or severely distressed
  - Medication to start with low dose, be time-limited and aimed at specific, recorded and quantified target symptoms and reviewed at least every 3 months, and reduced as soon as possible; the review should consider: side-effects, changes in cognition, changes in target symptoms
  - Alternatives to anti-psychotic medication considered. Other approaches to include a full assessment, including physical health, pain, depression etc. (with multi-disciplinary team input)
Driver: Reduced inappropriate use of anti-psychotic medications in accordance with NICE/SCIE guidelines.

Interventions

Current NICE-SCIE guidelines recommend the time-limited use of anti-psychotic medication with some people with dementia, despite risks to health and quality of life. Recommended use is only in relation to severe and distressing difficulties that have not responded to other interventions. CSSIW guidance reinforces the need for a review of such medication every 3 months at most.

In November 2009, an independent report commissioned by the Department of Health in England ‘The use of antipsychotic medication for people with dementia: Time for action’ was published (Banerjee, 2009). The report quantified the health risks of the use of these medications, attributing 1800 deaths and 1620 cerebrovascular accidents (CVA) to their inappropriate use.

Research studies consistently show that these medications have a relatively limited therapeutic effect in relation to agitation and challenging behaviour in dementia. Only a small proportion of patients show a worsening of their behavioural symptoms when the medication is withdrawn.

Banerjee’s report contains 11 recommendations, all of which were accepted by the Department of Health. Recommendation 4 states that ‘People with dementia should receive antipsychotic medication only when they really need it. To achieve this, there is a need for clear, realistic but ambitious goals to be agreed for the reduction of the use of antipsychotics for people with dementia. Explicit goals for the size and speed of this reduction, and improvement in the use of such drugs where needed, should be agreed and published locally following the completion of the baseline audit…’

Taking Banerjee’s estimate that up to a quarter of people with dementia are receiving anti-psychotic medication, this would mean that there could be 10,000 people with dementia in Wales in this category, with around 100 additional deaths and 90 CVAs attributable to their negative effects.

Context

This driver is concerned with people with dementia, where anti-psychotic medication is being considered; the person may be living in the community or resident in a care home.

Towards appropriate use

There are circumstances in which anti-psychotic medication may justifiably be used. These include situations where there is immediate risk of harm to the person or others, or a severe level of distress. Otherwise, alternative approaches should be utilised in the first instance. Where the medication is to be used, certain conditions should be followed carefully.
Improving Dementia Care

**Full discussion with patient and / or carers about possible benefits and risks of treatment.**

The increased risk of CVAs, negative effects on cognition and so on should be discussed, as well as possible benefits such as reduced distress and agitation.

**Assess for capacity and where person with dementia lacks capacity, follow ‘best interests’ process.**

As with all treatment decisions, the provisions of the Mental Capacity Act must be followed, and decision-making processes documented.

**Anti-psychotic medication to be used with people with dementia after other approaches have been tried (see NICE-SCIE, 2007), unless person at immediate risk of harming self or others or severely distressed.**

The reasons for prescribing should be documented, along with details of the alternatives that have been pursued and their outcomes.

**Medication to start with low dose, be time-limited and aimed at specific, recorded and quantified target symptoms.**

Medication should be reviewed at least every 3 months, and reduced as soon as possible. The review should consider:

- side-effects
- changes in cognition
- changes in target symptoms

Reviews should be documented, as specified, and medication withdrawn as soon as possible.

**Measures:**

For this intervention, process measures to be used include:

- Number of people with dementia who are receiving anti-psychotic medication
- Proportion of people with dementia who are on anti-psychotic medication where review within 3 months
- Proportion of people with dementia who have been on anti-psychotic medication for >9 months
- % compliance with care bundle (all 4 above interventions documented)
Applying the model for improvement

**Aim:** To ensure that where anti-psychotic medication is used with people with dementia, its use is in accordance with NICE-SCIE guidelines.

**Improvement monitoring:** Audit of case-notes and prescribing records

**Change required:** For a given care setting, or community service, establish a work group to consider audit data and identify areas that need to be addressed through PDSA cycles. Identify where the drugs are being initiated, and any obstacles to review or to providing alternative approaches.

Assessment tools

An audit tool / spreadsheet is available from the 1000 Lives Plus web-site: www.wales.nhs.uk/sites3/page.cfm?orgid=781&pid=48639#Dementia

**Examples of local practice**

- An audit was undertaken of use of anti-psychotics in local care homes registered for people with dementia; this included numbers receiving the medication, frequency of review etc.

**Top Tips**

- Consider training needs raised by local audits for e.g. GPs, care home staff
- Involve pharmacists in monitoring medication use and review

**Patient engagement**

Have information leaflets available for carers and people with dementia regarding the appropriate use of these medications.
Alternatives to anti-psychotic medication

Other approaches to include a full assessment, including physical health, pain, depression etc. (with multi-disciplinary team input)

Alternative approaches can only be identified through a process of careful assessment of the person and his/her situation.

There are numerous potential factors leading to a person with dementia becoming distressed or showing challenging behaviour, and in assessing these an individually tailored care plan can be devised that may be effective in reducing distress or in reducing the extent to which behaviour seen as difficult and challenging occurs.

Key factors to include in such an assessment, according to NICE-SCIE guidelines include:

- Physical health and possible undetected pain or discomfort
- Depression
- Side effects of medication
- Individual biography, including religious beliefs and spiritual and cultural identity
- Psychosocial factors
- Physical environmental factors
- Behavioural and functional analysis conducted by professionals with specific skills, in conjunction with carers and care workers

Measure:

For this intervention, process measures to be used include:

- Number of people with dementia prescribed anti-psychotic medication where distress was not severe AND there was no immediate risk of harm AND alternative approaches, based on a full assessment, had not been implemented.
Applying the model for improvement

**Aim:** To ensure alternatives to anti-psychotic medication are widely available

**Improvement monitoring:** Audit records of those who are prescribed anti-psychotic medication; survey knowledge and practices in care settings regarding management of challenging behaviour.

**Change required:** Establish multi-disciplinary work groups to identify areas where alternative approaches are not being used; address training and system requirements needed to address this using PDSA cycles. Involve voluntary sector in developing more creative approaches to engagement and stimulation.

**Assessment tools**

The Challenging Behaviour Scale (Moniz-Cook et al., 2001) is a useful scale for quantifying and monitoring difficult behaviour in care home settings, and can highlight residents where alternative approaches to medication should be considered at an early stage.

**Challenging Behaviour Scale:**


**Examples of local practice**

- One service has developed an in-reach team to work with care homes, developing skills in responding to and preventing challenging behaviour.

**Top Tips**

- Other therapeutic approaches recommended by NICE-SCIE for co-morbid agitation include:
  - aromatherapy,
  - multisensory stimulation,
  - therapeutic use of music and/or dancing,
  - animal assisted therapy
  - massage
  - reminiscence (in relation to depression and anxiety)
  - exercise (in relation to depression and anxiety)
These need to be tailored to individual preferences and abilities, and response monitored carefully.

- Keeping a careful record of difficult behaviour can often provide clues as to its management, recording exactly what happens, what else was happening at the time, who was present, and what the consequences of the behaviour were.

- Training in preventing challenging behaviour - through effective communication and good observation - is as important as ‘managing’ it when it occurs.

- In some situations, the problem is not so much the behaviour, but the effects it has on others - a good outcome can be when care-givers are less upset or distressed by a behaviour, perhaps because they have a better understanding of what lies behind it.

**Patient engagement**

A person-centred approach, which seeks to understand the person with dementia in the context of his/her life story, building on the person’s preferences, interests and personality style will inform and strengthen any attempt to pursue alternative approaches to anti-psychotic medication.
4. Improved support for care givers

These show the detailed elements of the interventions listed on the main driver diagram.

To increase support for care givers

- Carers involvement in care-planning
  - Carers to be involved in care-planning for the person with dementia
  - All carers offered Carers Assessment when care-plan for the person with dementia agreed
  - Detailed arrangements for emergency & crisis support in care plans with support available when required
  - A range of breaks to be available for carer respite.
- Educational and therapeutic interventions
  - Use of multi-component carer support programmes, including individual and group support
  - Evidence-based therapies, including individual psychological therapy for depression and anxiety related to care-giving.
  - Training for carers to be available on a regular basis
Improved support for caregivers

Care provided by family and friends represents the major source of support for people with dementia. Admission of people with dementia to care homes and hospital units often arises from a breakdown of the support network at home, rather than from the progression of the dementia. Carers of people with dementia are at increased risk of psychological distress, anxiety and depression.

Context

This driver applies to caregivers for people with dementia - usually family or friends, where the person with dementia lives in the community, with the caregiver or separately. These caregivers are sometimes described as ‘informal’, in the sense that they are not employed to carry out the role. Most aspects are also applicable where the person with dementia is resident in a care home.
Driver: Carers’ involvement in care planning

Effective care and support for people with dementia involves working in partnership with the person’s relatives and other key members of the support network. Care plans need to address the specific needs of carers; this will usually be the most effective means of meeting the needs of the person with dementia.

Interventions

*Carers to be involved in care-planning for the person with dementia.*

This is the cornerstone of partnership working. The expectation should be, with the appropriate consents, carers will be fully involved in the planning of care, and be able to play a key role in decision making. Where several family members are involved, it should not be expected that their perspectives and interests will always be identical, nor that their interests will always coincide with those of the person with dementia. Skilled care-planning involves, at times, mediating between and securing consensus from those with divergent views.

*All carers offered ‘Carers Assessment’ when care-plan for the person with dementia agreed.*

Carers have a right to receive an assessment of their needs as well (NICE-SCIE guidelines), but surveys of carers repeatedly show that either carers are not offered such an assessment, or if they are, that they do not realise that this is the case.

*Detailed arrangements for emergency and crisis support in care plans with support available when required.*

Many carers have reported that they gain considerable reassurance from knowing what would happen if an emergency or crisis arose, and that this knowledge actually helps them to continue caring for longer.

Arrangements might involve other family or friends, or statutory services, but should be detailed on the care-plan of which the carer holds a copy.

*A range of breaks to be available for carer respite.*

Many carers derive great benefit from breaks from care-providing, and they can help the carer maintain other roles and interests. The quality of the input provided to the person with dementia during the break is of great importance to many carers, and a relationship of trust with the care provider allows the carer to achieve maximum benefit from the break.

Breaks may vary from a ‘befriender’ visiting the person with dementia at home to a two-week stay in a residential setting. Matching the break to the needs
and preferences of the person with dementia and carer is vital, and so the availability of a wide range of breaks is required.

**Measures:**

For this intervention, process measures to be used include:

- Proportion of care-plans for people with dementia supported at home by family carers which include detailed and specific arrangements for emergency and crisis support.
- Proportion of care plans where carer has been involved in care planning.
- Proportion of care plans recording that a ‘Carers Assessment’ has been explicitly offered.

**Applying the model for improvement**

**Aim:** To ensure carers are fully involved in care-planning

**Improvement monitoring:** Audits of care plans will demonstrably provide evidence of involvement; range of breaks offered can also be extracted. Examine take-up of Carers Assessments.

**Change required:** Establish a joint agency working group (health and social care), and use PDSA cycles to identify where changes of practice or systems are needed. Identify and address barriers to carer involvement and to take-up of Carers Assessments.

**Assessment tools**

An audit tool / spreadsheet is available from the 1000 Lives Plus web-site: www.wales.nhs.uk/sites3/page.cfm?orgid=781&pid=48639#Dementia

**Top Tips**

- Where there is perceived conflict between views of the person with dementia and carer, have different members of the team work with each
- In discussing ‘Carers Assessments’ emphasise it is the carer’s needs that are being assessed, not their ability!
- It is always worth asking the carer what they think would make a real difference - often it’s not an expensive service that would tip the balance.
Driver: Educational and therapeutic interventions

NICE-SCIE guidelines recommend that carers be offered a range of interventions, and that carers’ assessments should specifically include evaluation of psychological distress and the psychosocial impact on the carer. This assessment should be on-going, and include any period after the person with dementia has entered a care home, as distress often continues.

Interventions

Use of multi-component carer support programmes, including individual and group support

NICE-SCIE recommend that these be tailored to the individual carer, and may include peer support groups, telephone and internet support and information, and involvement of other family members as well as the primary carer in family meetings.

Evidence-based therapies, including individual psychological therapy for depression and anxiety related to care-giving.

NICE-SCIE recommend psychological therapy, including cognitive behavioural therapy, conducted by a specialist practitioner, for carers who experience psychological distress and negative psychological impact.

Training for carers to be available on a regular basis.

Training courses might include communication, problem-solving, practical skills and available services and benefits.

Measures:

For this intervention, process measures to be used include:

- Number of carers participating in multi-component carer support programmes.
- Number of carers receiving individual psychological therapy for depression and anxiety related to care-giving.
Apply the model for improvement

Aim: To reduce distress and improve quality of life of carers of people with dementia

Improvement monitoring: Audit of carer interventions available, looking at up-take and referral routes.

Change required: Form working group, involving voluntary agencies working with carers and those responsible for delivery of psychological therapies. Identify gaps in provision and barriers to psychological therapy being offered to those carers in need of it. Use PDSA cycles to address these gaps and barriers.

Assessment tools
A number of tools are available to assess carer distress

Relatives Stress Scale:
Measuring the outcome of psychosocial intervention for family caregivers of dementia sufferers: a factor analytic study. Aging & Mental Health, 1(2), 166 - 175.


Windsor: NFER-Nelson.
http://tinyurl.com/n5wahb

Hospital Anxiety and Depression Scale:
http://tinyurl.com/39hezpy

Examples of local practice

- A memory clinic offers support groups for both people with dementia and carers after diagnosis.
- A service for young people with dementia included carers. Joint activities provided many opportunities for informal peer support between carers.
- A local branch of the Alzheimer’s Society runs regular training courses for carers, offering transport and a sitting service.
Top Tips

- Interventions for carers may be more effective when the person with dementia is involved also e.g. in psycho-education meetings and support groups.
- Alzheimer cafes provide a useful means of offering peer support and psycho-education, where the carer and person with dementia may attend together.
- Transport may be needed by some carers in order to use available interventions.
- Having someone stay with the person with dementia may be needed for some carers to make use of interventions.
- Peer support groups for carers need to be offered mindful of the stage of dementia the care-recipient is currently at; carers may have more common ground with those having similar experiences.
- Psychological therapy services may need to recognise that whilst depression and anxiety are common in carers, they are not the norm, and have been shown to respond to therapeutic input.
- Not everyone feels comfortable in a group where the focus is simply peer support. Structured enjoyable activities help people to relax and work together, offering more informal opportunities for support.

Patient engagement

Alzheimer’s Cafés, in their original Dutch concept, included professionals as well as carers and people with dementia. At such a forum, professionals have the opportunity to learn from the real ‘experts’, those living with dementia.

Some carers are able to take on a ‘mentoring’ role, offering support to ‘new’ carers, able to offer a voice of experience.
5. NHS mental health in-patient units for people with dementia

**Content Area**

**Drivers**

**Interventions**

- For all patients admitted, check history with family / other supporters.
- Physical health screen (examination and targeted investigations).
- Assess environmental needs - safety, stimulation, need for single room etc.
- Assess needs for assistance and maintaining skills with meals, toileting, self care etc. and ensure built into care plan and care provided accordingly.
- Involvement of family members and other supporters in the unit to be encouraged.
- Carers to be involved in care-planning for the person especially in relation to discharge planning with detailed arrangements for emergency & crisis support in care plans with support available when required.
- If the patient has a diagnosis of dementia when being discharged: all carers offered Carers Assessment.
- Assess for capacity for major decisions, and where person lacks capacity, follow ‘best interests’ process.
- A range of appropriate meaningful, failure-free activities to be available, including physical exercise. Frequency and enjoyment to be rated.
- Full discussion with patient and / or carers about possible benefits and risks of any proposed treatment with anti-psychotic medication.
Improved quality of care in NHS dementia in-patient units

The quality of care provided in care settings of all types is a major concern for people with dementia and their carers. Whether the facility is provided by the NHS or by a local authority or by the independent sector, the maintenance of dignity and care needs being met are paramount amongst the concerns expressed by people with dementia and carers.

Quality of care in care homes is the responsibility of the Care & Social Services Inspectorate Wales (CSSIW), and so this driver focuses on NHS provision.

Safety issues are a priority. The former Commission for Health Improvement documented several services in England in the recent past where there have been major short-comings in the quality of care in NHS dementia care units (e.g. Rowan ward, Manchester; CHI, 2003).

**Driver: On admission**

**Interventions**

Person-centred care requires the person to be known as an individual, and so the initial assessment process is an important starting process for getting to know the person.

For all patients admitted, check history with family / other supporters.

Family members and other supporters will have invaluable information regarding the person, his/her preferences, care needs and the circumstances leading up to the admission that will underpin the care-plan.

Physical health screen (examination and targeted investigations).

The person’s physical health will have a major influence on their condition, and should be evaluated soon after admission, with appropriate investigations being carried out.

Assess environmental needs - e.g. safety, stimulation, need for single room

It should be possible to gear the environment of a NHS dementia unit specifically to the needs of people with dementia, without the competing demands of, for example, an acute general hospital ward.

Helpful dementia environments demonstrate an unobtrusive concern for safety, a calm, relaxing atmosphere, with opportunities for interaction and activity, as well
as for privacy and quiet. The individual person’s needs within the context of an overall supportive environment will need to be assessed in the period after admission.

Assess needs for assistance and maintaining skills, e.g. with meals, toileting, self care, and ensure these are built into care plan and care provided accordingly

A person-centred approach is required, with an individual profile and care plan being drawn up, setting out clearly the areas where the person with dementia may require assistance, and taking into account the person's preferences. Information should be gathered from the patient and/or relatives and carers.

Measures:

For this intervention, process measures to be used include:

- Relatives’ satisfaction with care survey.
- % compliance with care bundle (All four interventions related to admission should be documented within 48 hours of admission).
- Observational audit (see below).

Applying the model for improvement

Aim: To ensure person-centred care is provided for all patients with dementia.

Improvement monitoring: Audits of case notes; results from relatives’ survey; observational audit.

Change required: Establish a multi-disciplinary work group to identify any gaps or barriers to person centred care arising from the audits and survey. Use PDSA cycles to address these and to improve the overall quality of the environment.

Assessment tools

Relatives’ survey form available from:
www.wales.nhs.uk/sites3/page.cfm?orgid=781&pid=48639#Dementia

Observational audit: consider the Royal College of Psychiatrists programme of Accreditations for In-patient Mental Health Services (AIMS) - there is a specific version for wards for older people (AIMS-OP).
www.rcpsych.ac.uk/quality/qualityaccreditationaudit/aims.aspx
Dementia Care Mapping is a more dementia-focused observational tool, looking at the impact of the ward on the well-being of people with dementia.
See: http://tinyurl.com/yb6dj4h

**Examples of local practice**

- A relatives’ survey was sent to all relatives of patients in two in-patient units - a 40% response rate was achieved.

**Top Tips**

- Ensure all domains within the admission checklist are completed.
- During conversation with family members identify any likes/dislikes and all care needs that the patient may have.
- Obtain a social history to provide you with information to engage in meaningful communication with the patient.
- Maintain regular contact with examining doctor and ensure test results are available as soon as possible.
- Obtain a brief care needs history to provide you with information to complete a meaningful care plan.
- Spend some time on the unit experiencing it in the way a patient would, in order to understand more about the environment and its effects.

**Patient engagement**

The person-centred care approach puts the person with dementia at the centre of the assessment and care-planning process - the person’s views and preferences and life story must be reflected fully.
Driver: Involving families

Families, and other carers, are a great resource for people with dementia.

Interventions

Involvement of family members and other supporters in the unit to be encouraged

From the outset, family involvement is to be encouraged. There needs to be a two-way flow of communication, so that the family are able to share their knowledge and understanding of the person with dementia with the ward, and, in turn, with the consent of the person with dementia, the ward should consult and inform the family and/or other carers regarding treatment plans, any changes and any problems occurring.

Some carers may wish to assist the person with care needs or in maintaining social engagement. Wherever possible, carers should be supported in continuing or adapting their care-giving role.

Carers to be involved in care-planning for the person especially in relation to discharge planning with detailed arrangements for emergency and crisis support in care plans with support available when required.

Involvement both in the care-plan whilst the person is in hospital and in planning discharge arrangements is essential for a successful outcome. At discharge, the carer should be satisfied with all the arrangements that have been put in place, and feel able to take on or continue the role of carer.

Having specific emergency and crisis support written into the care plan is a great source of reassurance to many carers, even if it is never used.

If the patient has a diagnosis of dementia when being discharged: all carers offered Carers Assessment.

Carers have a right to an assessment of their needs. Discharge from hospital provides a good opportunity to offer this to those who will be providing care (see also Improved Support for Caregivers section, page 42).

Measure:

For this intervention, process measures to be used include:

- Relatives’ satisfaction with care survey.
Applying the model for improvement

Aim: To ensure families and other carers are fully involved in the unit.

Improvement monitoring: Regular use of relatives’ survey form.

Change required: Establish multi-agency work group with carers’ organisation representatives and ward staff to consider actions to increase family involvement, drawing on responses to relatives’ survey. Use PDSA cycles to implement and monitor changes.

Assessment tools

Relatives’ survey form available from: www.wales.nhs.uk/sites3/page.cfm?orgid=781&pid=48639#Dementia

Examples of local practice

The Mental Health Services for Older People Directorate at Cardiff & Vale UHB have been conducting relatives’ surveys on a regular basis for some years. The survey focuses on specific aspects of care including communication and the care environment, and is based on the Fundamentals of Care approach. Action is taken based on the survey results.

Top Tips

- Ensure family and other supporters are involved from the day of admission.
- Provide carer with a copy of the final care plan with patient’s agreement.
- Ensure the involvement of family and other supporters in planned unit developments.
- Provide carer with details of a named contact and telephone number to use following discharge in case any difficulties arise post-discharge (e.g. Community Nurse, Social Worker, GP)
- In circumstances where patients refuse permission to allow the carer to be involved in decisions about their future care, carers should be informed of this, and their right to a Carer’s Assessment reinforced. (There may be occasions where a carer’s needs or wishes conflict with the patient’s aspirations and in these situations staff teams should review the care plan and endeavour to find a realistic solution for all concerned.)
Driver: Interventions in in-patient units

Interventions

Assess for capacity for major decisions, and where person lacks capacity, follow ‘best interests’ process.

The Mental Capacity Act provides the legal framework for decision making for all health and social care staff, in relation to people who may lack capacity. Capacity is assumed, until an assessment indicates that the person lacks capacity in relation to a particular decision.

If the person is likely to regain capacity e.g. after recovery from acute physical illness, the decision should be delayed if possible. The person must be as fully involved with the decision as possible, even if they lack capacity. The needs of the person for an independent advocate should be considered. All assessments of capacity and decisions made should be fully documented.

A range of appropriate meaningful, failure-free activities to be available, including physical exercise (frequency and enjoyment to be rated).

Many care environments are characterised by a lack of activity and interaction. A therapeutic environment should offer a range of opportunities for activity, occupation and engagement.

These should be tailored to the interests, preferences and ability of the person with dementia, so that the person is able to engage at a level where he/she can succeed with the task, or components of it. Levels of engagement with, and enjoyment of, activities should be documented, and care plans adjusted accordingly.

Meaningful activities are created to tap into a person’s past skills, memories and interests. These do not have to always be structured but do need to stimulate the senses and encourage participation.

Activities and therapies may include:

- aromatherapy
- story-telling
- music
- exercise
- art

Other specially-designed activity programmes can also be used. Activities may involve movement or quiet time in conversation. The true focus may not be so much about the activity itself but rather the quality and joy of the interaction.
**Full discussion with patient and / or carers about possible benefits and risks of any proposed treatment with anti-psychotic medication.**

If anti-psychotic medication is used, it should be started with low dose, be time-limited and aimed at specific, recorded and quantified target symptoms and reviewed at least every week.

Anti-psychotic medication is discussed in detail in section 3. The same considerations apply in NHS dementia in-patient units, except that review should be on a weekly basis.

**Measure:**

For this intervention, process measures to be used include:

- Results from observational audit.
- Relatives’ satisfaction with care survey.
- Audit of use of anti-psychotic medication - compliance with NICE-SCIE guideline.

---

**Applying the model for improvement**

**Aim:** To ensure the person with dementia receives appropriate therapeutic interventions.

**Improvement monitoring:** Monitor using audits and regular relatives’ survey.

**Change required:** The change required may be to increase the range of activities on offer, offering alternative approaches to anti-psychotic medication in relation to challenging behaviour. Establish a multi-agency working group - including voluntary agencies that may have a role to play in supporting a range of activities. Use PDSA cycles to pilot and evaluate different approaches.

**Assessment tools**

Relatives’ survey form available from: www.wales.nhs.uk/sites3/page.cfm?orgid=781&pid=48639#Dementia

Observational audit: consider the Royal College of Psychiatrists programme of Accreditations for In-patient Mental Health Services (AIMS) - there is a specific version for wards for older people (AIMS-OP).

www.rcpsych.ac.uk/quality/quality,accreditationaudit/aims.aspx
Dementia Care Mapping is a more dementia-focused observational tool, looking at the impact of the ward on the well-being of people with dementia. See: http://tinyurl.com/377d4ba

A number of resources are available for assisting with identifying appropriate activities e.g. the Pool Activity Level (3rd edition) 2007; Jessica Kingsley Publishers

**Top Tips**

- Simple assessment tools can help staff to understand the types of activities that might benefit a person with dementia.
- It is important that offering therapeutic activities is seen as a role for each member of staff, not just a designated person.
- Life story work can be helpful in understanding more about the person’s interests and preferences.
- Creative activities - including art, collage, music, baking etc. can provide a strong source of self-worth for those participating.

**Patient engagement**

Activities should be tailored to individual preferences, with patients fully involved in expressing their views.
Helpful Resources


http://tinyurl.com/3abkfxs


Royal College of Psychiatrists accreditation programmes:

For Memory Clinics:

www.rcpsych.ac.uk/quality/quality,accreditationaudit/
memoryservicesaccreditation.aspx

For NHS in-patient mental health units:

www.rcpsych.ac.uk/quality/quality,accreditationaudit/aims.aspx
## Appendix A: Tools developed to assist in process measures

### A.1 Memory Assessment Service (MAS) Audit sheet

<table>
<thead>
<tr>
<th>Action</th>
<th>Carried out?</th>
<th>Date</th>
<th>Initials of responsible staff member</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient ID ..................................................................................</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date of Birth ............................................................................</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date of referral from primary care to MAS (referral letter date) .........</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date first symptoms noticed by person and/or supporters (month/year) ..........</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Action</th>
<th>Carried out?</th>
<th>Date</th>
<th>Initials of responsible staff member</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-diagnostic assessment counselling?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I.e. explanation to patient of assessment process, possible outcomes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neuropsychological assessment? (Formal testing over and above MMSE) .....</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain Scan?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical health screen with appropriate rigour?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>VERBAL feedback provided to patient* on diagnosis to include relevant information, guidance re future planning, appropriate interventions, need for repeat assessments?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WRITTEN feedback provided to patient* on diagnosis to include relevant information, guidance re future planning, appropriate interventions, need for repeat assessments?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discussion with patient* on potential interventions on offer to promote adjustment and adaptation and promote social networks?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If dementia, was referral made to Alzheimer’s Society and/or other relevant carers’ organisations?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Family members will also usually be included in the feedback, according to patient preference
Appendix B - Frequently Asked Questions

Q. Who should carry out the audits and collection of data?
A. Ownership of the data should be the responsibility of the frontline staff, implementing improvement is the responsibility of all multi disciplinary staff. If the work is carried out by a single person it very difficult to sustain the work over a long period of time.

Q. Who can help me with analysing the information and measurement?
A. There is a separate ‘How to Guide’ on measurement which provides advice on how to take forward the required measurements for improvement. Within your organisation there will be individuals who have been trained in improvement methodologies through the Safer Patient Initiative and 1000 Lives Plus.

Q. What is the target for the amount of time between referral from primary care and feedback being given in memory assessment services?
A. No specific target is given for this or for the time between referral and the person being seen. This work takes the view that services should be working for improvement based on monitoring and understanding current performance and barriers to change, making changes that make sense in the context of improving local services.

Reporting of key indicators in a standard way will allow comparisons across services, and encourage further work on understanding differences through a collaborative approach.

Q. If anti-psychotic medication is so harmful, should it not be banned for people with dementia?
A. The aim here is for interventions to be used in line with current evidence-based guidelines and best practice. NICE-SCIE guidelines recommend the use of anti-psychotic medication for people with dementia in certain restricted circumstances, and this forms the basis of the indicators on this topic.

Q. How do these targets relate to the National Dementia Action Plans?
A. These targets were produced alongside the dementia action plans in Wales, and are consistent with the principles underlying the plans. These targets are established within an NHS performance management framework, the Annual Operating Framework (AOF), whereas the plans have a broader remit including the whole range of our community’s response to dementia, including raising awareness, health promotion, social care and third sector involvement.
Although improving NHS services forms only part of this response, achieving it would make a significant difference to the lives of people with dementia and their supporters.

**Q. How do the driver diagrams relate to Clinical Guidelines?**

A. Dementia care is a complex process, and the driver diagrams have aimed to highlight certain key indicators of a quality service. They are NOT comprehensive, and practitioners should refer to the full NICE-SCIE Guidelines on dementia for more detailed, thorough recommendations on the detail of providing good quality care. The components highlighted in this document are necessary but not sufficient for good quality care.
Appendix C - Measures and Operational Definitions

Tools have been hyperlinked to this document where possible. Otherwise please go to the 1000 Lives Plus website for all the improvement tools listed within this document and also for shared care bundles, care pathways and improvement tools developed at local level by frontline teams across Wales.

www.wales.nhs.uk/sites3/page.cfm?orgid=781&pid=48639#Dementia

Reporting

<table>
<thead>
<tr>
<th>Measure</th>
<th>Operational definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>To improve memory assessment services</strong></td>
<td></td>
</tr>
<tr>
<td>Time between first onset of symptoms reported by patients and/or supporters and referral to memory assessment service.</td>
<td>It is recognised that reports of onset are not always reliable; pin down to nearest month if possible when significant cognitive impairments were noted, affecting daily life.</td>
</tr>
<tr>
<td>Percentage compliance with care bundle.</td>
<td>The audit sheet (Appendix A1) can be used. Note that each of these actions should be considered and discussed with the person; there may be sound clinical reasons why an action is inappropriate in a particular case. Lack of resource is not a clinical reason!</td>
</tr>
<tr>
<td>Median time from referral by GP, social worker or other primary care worker to feedback interview.</td>
<td>Median time is taken to allow for occasional outliers taking a long time due to missed appointments, concurrent illnesses etc.</td>
</tr>
<tr>
<td>Percentage compliance with the care bundle.</td>
<td>The audit sheet (Appendix A1) can be used. Note that each of these actions should be considered and discussed with the person; there may be sound clinical reasons why an action is inappropriate in a particular case. Lack of resource is not a clinical reason.</td>
</tr>
<tr>
<td><strong>To improve care on general hospital wards</strong></td>
<td></td>
</tr>
<tr>
<td>Proportion of patients admitted where admission checklist indicates that information regarding any dementia diagnosis was sought.</td>
<td>As percentage of at risk group i.e. over 65s. Numerator is number of patients where the information was sought; denominator is total number of admissions aged 65 and over.</td>
</tr>
<tr>
<td>Proportion of patients with delirium where delirium assessment pathway was followed.</td>
<td>Will need an audit survey to identify patients with delirium at a given time point (denominator) and those on the delirium assessment pathway (numerator).</td>
</tr>
<tr>
<td>Number of patients following agreed dementia care pathway.</td>
<td>As percentage of at risk group i.e. over 65s. Numerator is number of patients where the information was sought; denominator is total number of admissions aged 65 and over.</td>
</tr>
<tr>
<td>----------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Proportion of people with dementia on anti-psychotic medication.</td>
<td>Will need an audit survey to identify patients with dementia at a given time point (denominator) and those on anti-psychotic medication (numerator).</td>
</tr>
<tr>
<td>Relatives’ satisfaction with care survey.</td>
<td>Item 4 ‘satisfaction with overall quality of dementia care’ is key indicator here.</td>
</tr>
</tbody>
</table>

### To improve community care (including in care homes)

<table>
<thead>
<tr>
<th>Number of people with dementia who are receiving anti-psychotic medication.</th>
<th>In a given care setting, a frequency count of those receiving this class of medication.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proportion of people with dementia who are on anti-psychotic medication where review within 3 months.</td>
<td>A review is defined as a documented consideration of the use of the medication, where the person is seen by the clinician, and side effects, changes in cognition and changes in target symptoms are documented. Numerator is number of people with dementia on the medication who have been reviewed within the last 3 months; denominator is number of people with dementia on the medication for a period of over 3 months.</td>
</tr>
<tr>
<td>Proportion of people with dementia who have been on anti-psychotic medication for &gt;9 months.</td>
<td>Denominator is number of people with dementia on anti-psychotic medication; numerator is number of people where the medication was started more than 9 months ago, and have been on the medication continuously, or with breaks of less than a month.</td>
</tr>
<tr>
<td>Percentage compliance with care bundle.</td>
<td>All 4 actions should be documented for compliance to be recorded.</td>
</tr>
<tr>
<td>Number of people with dementia prescribed anti-psychotic medication where distress was not severe AND there was no immediate risk of harm AND alternative approaches, based on a full assessment had not been implemented.</td>
<td>Can be expressed as a percentage of total number receiving anti-psychotic medication, reflecting extent of inappropriate use.</td>
</tr>
</tbody>
</table>
### To increase support for care givers

<table>
<thead>
<tr>
<th>Metric</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proportion of care-plans for people with dementia supported at home by family carers which include detailed and specific arrangements for emergency and crisis support.</td>
<td>Numerator is number of care plans which included these arrangements; denominator is number of care plans examined of people with dementia supported at home by a family carer.</td>
</tr>
<tr>
<td>Proportion of care plans where carer has been involved in care planning.</td>
<td>Numerator is number of care plans where it is explicit that the carer has been involved in care planning; denominator is number of care plans examined, excluding any where there is no identified carer.</td>
</tr>
<tr>
<td>Proportion of care plans recording that a Carers Assessment has been explicitly offered.</td>
<td>Numerator is number of care plans where it is explicit that a Carers Assessment has been offered; denominator is number of care plans examined, excluding any where there is no identified carer.</td>
</tr>
<tr>
<td>Number of carers participating in multi-component carer support programmes.</td>
<td>Will require a survey of carer support programmes in the locality - identifying the numbers of carers who are supporting people with dementia.</td>
</tr>
<tr>
<td>Number of carers receiving individual psychological therapy for depression and anxiety related to care-giving.</td>
<td>Will require a survey of those providing psychological therapy in the locality.</td>
</tr>
</tbody>
</table>

### To improve quality of care in NHS dementia in-patient units

<table>
<thead>
<tr>
<th>Metric</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relatives’ satisfaction with care survey</td>
<td>Questions 1-5 relate to Admission</td>
</tr>
<tr>
<td>Percentage compliance with care bundle All admission-related interventions documented within 48 hours of admission.</td>
<td>All need to be documented for compliance to be recorded.</td>
</tr>
<tr>
<td>Observational audit (see below).</td>
<td>Extent to which care is based on person’s life story and preferences and extent to which needs for care are met are relevant for the On admission driver.</td>
</tr>
<tr>
<td>Relative’s satisfaction with care survey.</td>
<td>Items 6, 7, 9, 11 and 13 are most relevant to the Involving families driver.</td>
</tr>
<tr>
<td>Results from observational audit.</td>
<td>Range of activities, frequency and enjoyment are relevant for the Interventions in in-patient units driver.</td>
</tr>
<tr>
<td>Relatives’ satisfaction with care survey.</td>
<td>Items 8, 9 and 10 are relevant to the Interventions in in-patient units driver.</td>
</tr>
<tr>
<td>Audit of use of anti-psychotic medication - compliance with NICE-SCIE guideline.</td>
<td>See process measures in section 3, but review within 1 week (instead of 3 months).</td>
</tr>
</tbody>
</table>
Appendix D - Setting up your team

Achieving improvements that reduce harm, waste and variation at a whole-organisation level needs a team approach: one person working alone, or groups of individuals working in an uncoordinated way will not achieve it and this applies equally at all organisational levels.

Whether your improvement priorities relate to 1000 Lives Plus content areas, national intelligent targets or other local priorities, you need to consider three different dimensions in putting your team together:

- Organisation level leadership.
- Clinical or technical expertise.
- Frontline leadership.

There may be one or more individuals on the team working in each dimension, and one individual may fill more than one role, but each component should be represented in order to achieve sustainable improvement.

**Organisation level leadership**

An Executive, or equivalent level Director, should always be given delegated accountability from the Chief Executive for a specific content area; and all staff working on the changes should know who this is. This individual needs sufficient influence and authority to allocate the time and resources necessary for the work to be undertaken. It is likely that accountability will be further delegated to Divisions, Clinical Programme Groups or Directorates and this can help to build ownership and engagement at a more local level. However, it is essential that the leader has full authority over the areas involved in achieving the improvement aim. As changes spread more widely, crossing organisational boundaries, appropriate levels of delegation will need to be reviewed.

When working with frontline teams, it is essential for organisational level leaders to have an understanding of the improvement methodology and to base conversations around the interpretation of improvement data. Reporting of progress to higher organisational levels should also use a consistent data format so that the Executive level leader can report to the Board on progress.

**Clinical/Technical Expertise**

A clinical or technical expert is someone who has a full professional understanding of the processes in the content area. It is critical to have at least one such champion on the team who is intimately familiar with the roles, functions, and operations of the content area. This person should have a good working relationship with colleagues and with the frontline leaders, and be interested in driving change in the system. It is important to look for clinicians or technical professionals who are opinion leaders in the organisation (individuals sought out for advice who are not afraid to try changes).
Patients can provide expert advice to the improvement team, based on their experience of the system and the needs and wishes of patients. A patient with an interest in the improvement of the system can be a useful member of the team. Additional technical expertise may be provided by an expert on improvement methodology, who can help the team to determine what to measure, assist in the design of simple, effective measurement tools, and provide guidance on the design of tests.

**Frontline leadership**

Frontline leaders will be the critical driving component of the team, assuring that changes are tested and overseeing data collection. It is important that this person understands not only the details of the system, but also the various effects of making changes in the system. They should have skills in improvement methods. This individual must also work effectively with the technical experts and system leader. They will be seen as a bridge between the organisation leadership and the day-to-day work.

Frontline leaders are likely to devote a significant amount of their time to the improvement work, ensuring accurate and timely data collection for process and outcome measures related to the frontline team.

**Characteristics of a good team member**

In selecting team members, you should always consider those who want to work on the project rather than trying to convince those that do not. Some useful questions to consider are the following:

- Is the person respected for their judgment by a range of staff?
- Do they enjoy a reputation as a team player?
- What is the person’s area of skill or technical proficiency?
- Are they an excellent listener?
- Is this person a good verbal communicator within and in front of groups?
- Is this person a problem-solver?
- Is this person disappointed with the current system and processes and passionately want to improve things?
- Is this person creative, innovative, and enthusiastic?
- Are they excited about change and new technology?
Appendix E - The Model for Improvement

Successful improvement initiatives don’t just happen - they need careful planning and execution. There are many things to consider and techniques to employ, which are captured in the driver diagram on page 67. The rest of this section explains the primary drivers and where to get more help in using them.

In any improvement initiative you need to succeed in three areas. You need to generate the Will to pursue the changes, despite difficulties and competing demands on time and resources. You need the good Ideas that will transform your service. Finally you need to Execute those ideas effectively to get the change required.

Will

The interventions you need to build Will are explained in the ‘Leading the Way to Safety and Quality Improvement’ and ‘How to Improve’ guides. They concentrate on raising the commitment levels for change and then providing the project structure to underpin improvement approaches. Spreading changes to achieve transformative change across the whole health system requires strong leadership. We need to create an environment where there is an unstoppable will for improvement and a commitment to challenge and support teams to remove any obstacles to progress.

Ideas

The interventions in this guide describe ideas which evidence shows to be effective for achieving changes that result in improvements. It gives examples from organisations that have achieved them and also advice based on their experience. Methods and techniques for generating new ideas or innovative ways to implement the evidence can be found in the ‘How to Improve’ guide and other improvement literature.

Execution

However, to bring these ideas into routine practice in your organisation, it is essential that you test the interventions and ensure that you have achieved a reliable change in your processes before attempting to spread the change more widely.

1000 Lives Plus uses the Model for Improvement (MFI) which is a proven methodology as the basis for all its improvement programmes. It requires you to address three key questions and then use Plan-Do-Study-Act (PDSA) cycles to test a change idea. By doing repeated small-scale tests, you will be able to adapt change ideas until they result in the reliable process improvement you require. Only then are you ready to implement and spread the change more widely.
Model for Improvement

Driver Diagram

**Aim**

**Primary drivers**

Will

**Secondary drivers**

Create an organisational culture and environment for improvement

**Interventions**

Engage senior Leadership

Make links to organisation goals

Form teams

Build skills

Raise awareness

Appoint clinical champions

**Ideas**

Evidence Base (The what to)

Use the relevant content area ‘How to Guide’ to assess the latest evidence of best practice

**Execution**

Improvement Methodology (The how to)

The Model for Improvement

What are you trying to accomplish?

How will you know that a change is an improvement?

What change can you make that will result in improvement?

Establish reliable process

PDSC cycles: Test - implement - spread - sustain

Use reliability model

Set SMART aims

Communicate aims

Use project charter to provide structure

Understand what to measure

Use 7 step measurement process

Map the process

Use creative thinking

Consult Faculty members to agree standards to be achieved

Use critical sub sets of key content areas to improve the outcome

To deliver patient safety and quality initiatives for Health Boards and Trusts
Model for Improvement - PDSA Cycle

What are we trying to accomplish?
How will we know that a change is an improvement?
What change can we make that will result in improvement?

For more guidance on using the Model for Improvement, see the ‘How to Improve’ guide.

Seven Steps to Measurement

1. Decide aim
2. Choose measures
3. Define measures
4. Collect data
5. Analyse & present
6. Review measures
7. Repeat steps 4-6
One area that bears extra attention is measurement because we have found that this is often the Achilles heel of improvement projects. When measuring your progress, follow the Seven Steps to Measurement shown on page 35 and covered in more detail in the ‘How to Improve’ Guide.

The key is to go round the Collect-Analyse-Review cycle frequently:

- **Collect** your data
- **Analyse** - turn it into something useful like a run chart
- **Review** - meet to decide what your data is telling you and then take action

Successful improvement projects all have clear aims, robust measurement and well-tested ideas. Use the ‘How to Improve’ guide to ensure your projects have all three.

**What are we trying to accomplish?**

You will need to set an aim that is Specific, Measurable, Achievable, Realistic and Time-bound (SMART). Everyone involved in the change needs to understand what this is and be able to communicate it to others.

**How will we know that change is an improvement?**

It is essential to identify what data you need to answer this question and how to interpret what the data is telling you. The improvement methodology ‘How to Guide’ provides detailed information on the tools, tips and information you need to achieve this, and includes the following advice:

<table>
<thead>
<tr>
<th><strong>Plot data over time</strong></th>
<th>Tracking a few key measures over time is the single most powerful tool a team can use.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Seek usefulness, not perfection.</strong></td>
<td>Remember, measurement is not the goal; improvement is the goal. In order to move forward to the next step, a team needs just enough data to know whether changes are leading to improvement.</td>
</tr>
<tr>
<td><strong>Use sampling.</strong></td>
<td>Sampling is a simple, efficient way to help a team understand how a system is performing.</td>
</tr>
<tr>
<td><strong>Integrate measurement into the daily routine.</strong></td>
<td>Useful data is often easy to obtain without relying on information systems.</td>
</tr>
<tr>
<td><strong>Use qualitative and quantitative data.</strong></td>
<td>In addition to collecting quantitative data, be sure to collect qualitative data, which is often easier to access and highly informative.</td>
</tr>
<tr>
<td><strong>Understand the variation that lives within your data.</strong></td>
<td>Don’t over-react to a special cause and don’t think that random movement of your data up and down is a signal of improvement.</td>
</tr>
</tbody>
</table>
What change can we make that will result in improvement?

The interventions in this guide describe a range of change ideas that are known to be effective. However, you need to think about your current local systems and processes and use the guide as a starting point to think creatively about ideas to test. The improvement methodology guide gives more advice to support you in generating ideas.

Spreading changes to achieve transformative change across the whole health system requires strong leadership. We need to create an environment where there is an unstoppable will for improvement and a commitment to challenge and support teams to remove any obstacles to progress. The guide on ‘Leading the Way to Safety and Quality Improvement’ gives detailed information on interventions that will support this. However, the Model for Improvement, PDSA cycles and process measurement lie at the heart of the transformative change we seek.
Improving care, delivering quality

If we can improve care for **one person**, then we can do it for **ten**.

If we can do it for ten, then we can do it for a **100**.

If we can do it for a 100, we can do it for a **1000**.

And if we can do it for a 1000, we can do it for **everyone in Wales**.

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