

Greater Manchester and Eastern Cheshire Strategic Clinical Networks

MANCHESTER

Dementia interactive care pathway toolkit

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Overview pathway

Using this ICP

This integrated care pathway has been developed to help clinicians understand the route a person with dementia may follow in order to receive appropriate care to manage the disease. It will support the decision making process to help understand which therapy the person should receive and then enable clinicians to understand the process for referral. The framework can then be customised for any locality.

Section 1 provides the overall pathway and accompanying information and resources

Section 2 is the Greater Manchester SCN Dementia Competency Framework arranged through the Well Pathway Framework Domains these domains will also be references throughout the pathway

Navigation

This ICP is an interactive pdf that you can easily navigate using the menu tabs above and tabs at the side. There are also links and icons in the pathway itself that you can use to navigate around the tool.

Summary

• NHS Dementia Well pathway Framework Domains show specific areas of the pathway and how individual services link together

Icons throughout the pathway highlight where you can click to find more information -

- **Key performance indicators** (KPIs) are suggested for how to measure whether the pathway is working effectively. These are measurable elements in the pathway, either quantitative, (e.g. fewer emergency attendances), or qualitative (e.g. positive experiences reported through the friends and families test). Quality Indicators (QIs) are developed in partnership with clinicians and designed to be used for benchmarking and audit of services. A full range of QIs can be found on the <u>HSCIC website</u>.
- **Additional information** gives more detail on a specific part of the pathway anything from national guidance to activity needed, to commissioning recommendations.













Overview pathway

Dementia in Sustainability and Transformation Plans covers parts of the pathway that might benefit from, or are reliant on, specific governance structures being in place. This might include, for example, a specific group of professionals working as a team under one manager, or a particular formal working arrangement across health and social care professionals in one service.

Information indicates further relevant information at that point in the pathway.

References

Printing

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This ICP tool is designed to be interactive and to be used electronically. The pdf document itself is very large so you may want to select a page range before printing. If you would like to print the full integrated care pathway only, click on the print icon below.



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Acknowledgements

Faculty

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Dementia in Sustainability and Transformation Plans







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Dementia United, <u>www.dementiaunited.net</u> Greater Manchester, Lancashire and South Cumbria Strategic Clinical Networks London Clinical Networks NHS Bury Clinical Commissioning Group Yorkshire and the Humber Clinical Networks

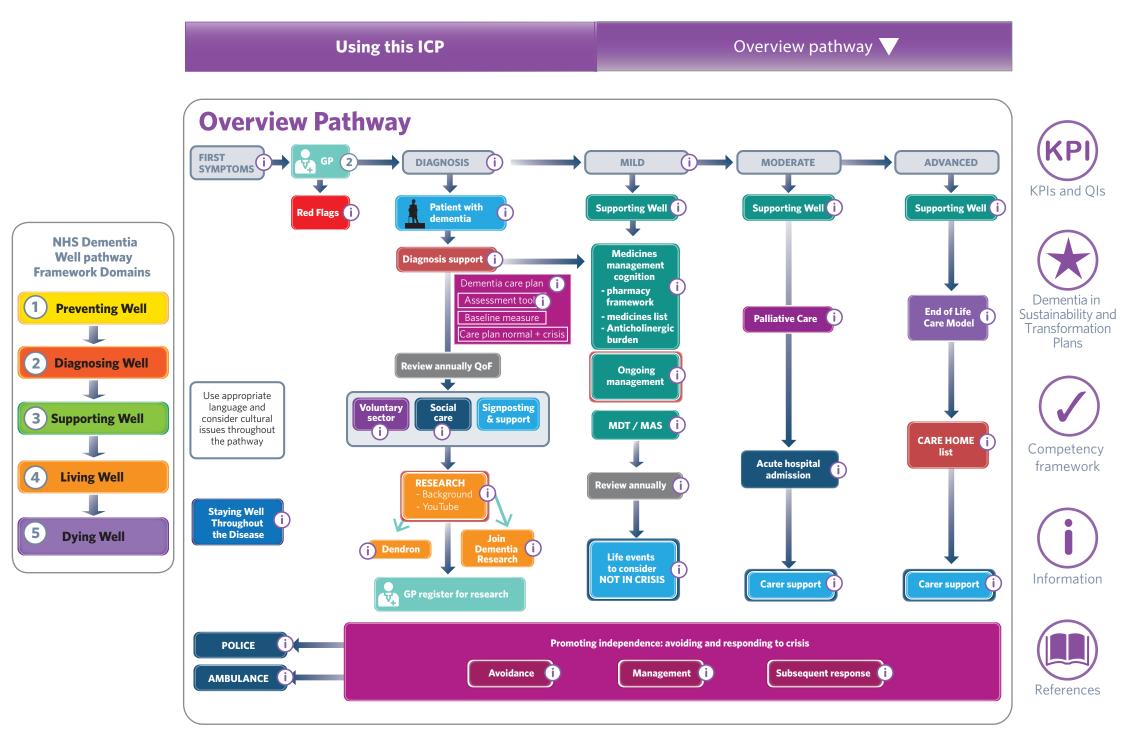






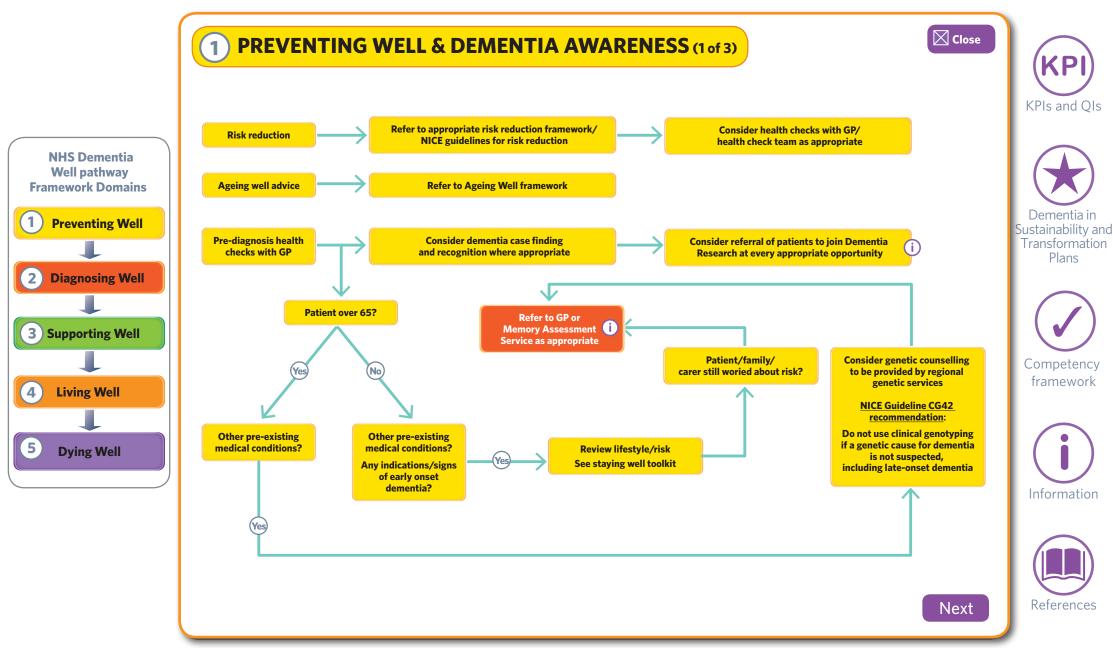






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1 PREVENTING WELL & DEMENTIA AWARENESS (2 of 3)

NHS Dementia Well pathway Framework Domains 1 Preventing Well 2 Diagnosing Well 3 Supporting Well 4 Living Well 5 Dying Well

Preventing Well Standards 1 (developed by Dementia United)

- Each locality will achieve uptake of NHS health checks comparable with the top 20% nationally and dementia screening will be specifically documented in these checks
- Measure:
- Health Checks Offered
- Health Checks Uptake

Source: Public Health England, Quarterly (http://fingertips.phe.org.uk/profile/nhs-health-check-detailed/data)

Dementia awareness:

- Consider the specific needs of individuals and communities
- People with dementia or early signs of dementia from ethnic minority (EM) communities should have their needs met by improving awareness among EM communities to combat stigma; tailor services to meet their needs within their communities, e.g. outreach, information; train staff in culturally acceptable care and meet the needs of carers
- Carers and family should receive training on basic awareness of dementia, coping mechanisms and services available to them through carer training programmes

Ageing well:

- Age is the biggest risk factor for dementia and the risk of developing dementia increases significantly with age
- Increased risk may be due to factors associated with ageing such as higher blood pressure in midlife, changes to nerve cells, DNA and cell structure, weakening of the body's natural repair systems, changes in the immune system
- NICE guideline 16 recommendations on promoting a healthy lifestyle to reduce the risk of or delay the onset of disability, dementia and frailty











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1 PREVENTING WELL & DEMENTIA AWARENESS (3 of 3)

Risk reduction:

NHS Dementia

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NICE guideline CG42 recommends:

- In middle-aged and older people, review and treat vascular and other risk factors for dementia, such as smoking and excessive alcohol use
- For the secondary prevention of dementia, vascular and other modifiable risk factors (for example high blood pressure, stroke, type 2 diabetes) should be reviewed in people with dementia

Dementia case finding in high-risk patients

- Should include those with Parkinson's, learning disabilities, care home residents with vascular risk factors, high alcohol consumption, and stroke
- Consider codes suggestive of dementia old EMIS codes, medications used to treat dementias Alzheimer's disease, Parkinson's disease dementia (not just current use; ever used), outcome of referrals to memory clinic and specific populations
- May include brief cognitive testing or use of a dementia single question
- Can be facilitated by learning disability teams; community specialist Parkinson's nurse; GP care home locally enhanced service; practice nurse involvement in chronic disease clinics; community matrons where available

Referral to Join Dementia Research (JDR)

- The focus of JDR is to increase the recruitment of volunteers, increase the numbers on the JDR register, match them to appropriate studies and increase participation whilst informing volunteers of research opportunities
- Anyone, with or without dementia, can register as a volunteer or sign-up for someone else, providing that you have their consent. Signing up is the first step in becoming involved in supporting vital research studies

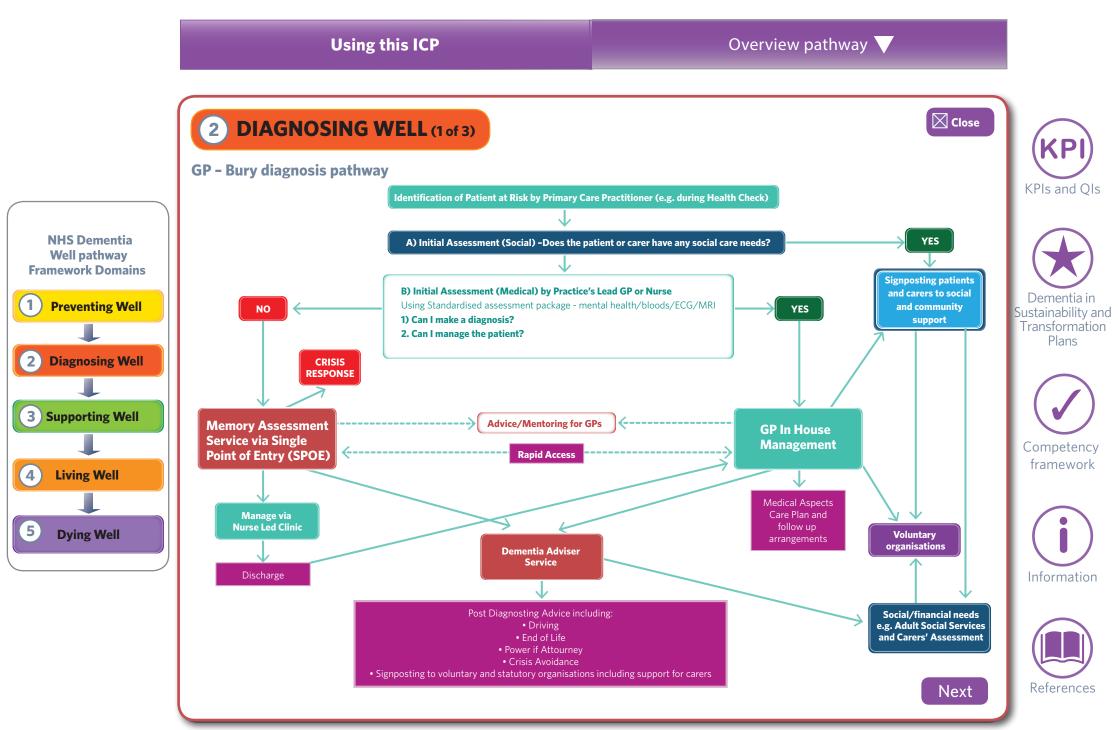




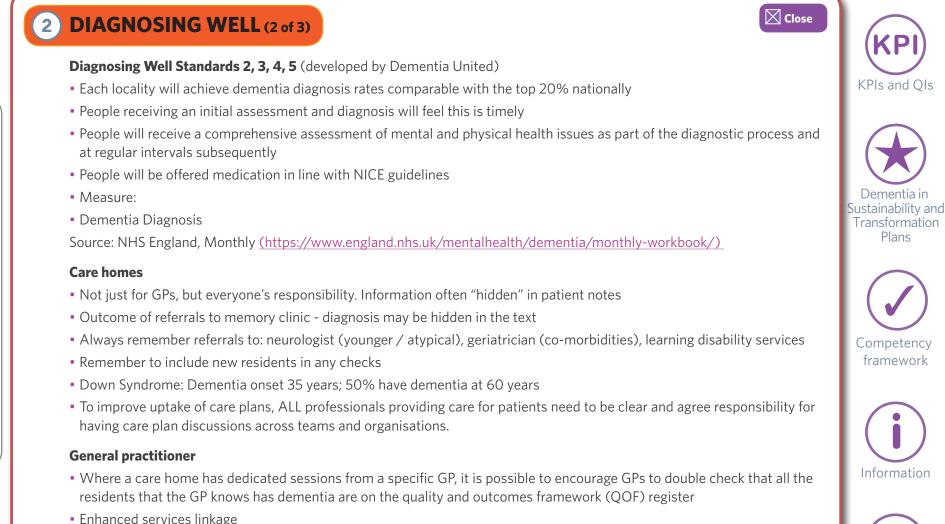








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• Initiatives to improve diagnosis in care homes can support the existing focus of aligning GP practices to specific homes

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2 DIAGNOSING WELL (3 of 3)

Secondary care

- Activity will include direct access services, unbundled services (excluding critical care) and secondary care services which cannot be allocated to more specific settings.
- Mental health secondary care services should also be included within this care setting

Other settings

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- Includes prison healthcare, hospice care, continuing care, intermediate care, respite care; free nursing care should be included within this setting
- Social care and learning disability services should be included within this setting unless otherwise specified by the mappings
- Patients with dementia can be seen by a whole range of professionals during their journey. Education and better understanding of the condition can facilitate staff to refer patients to the right service
- If in doubt, always refer to appropriate setting (e.g. GP, memory assessment, dementia specialist nurse or hospital team, care of the elderly consultant, geriatrician, consultant psychiatrist, etc) for assessment

Source: Care setting definitions

(https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212915/Care-Setting-Definitions.pdf)

Following diagnosis a care plan might include:

- A formal diagnosis and review period
- Additional psychological support
- Early intervention: drug and non-drug approaches
- Information provision
- Future care planning including advanced care planning

To support immediate and ongoing post-diagnostic support you might want to consider:

• Holistic and person-centred care including mental health, memory loss, oral health, diet and nutrition, physical health, physical activities, cognitive impairments, social inclusion and wellbeing, housing and financial support



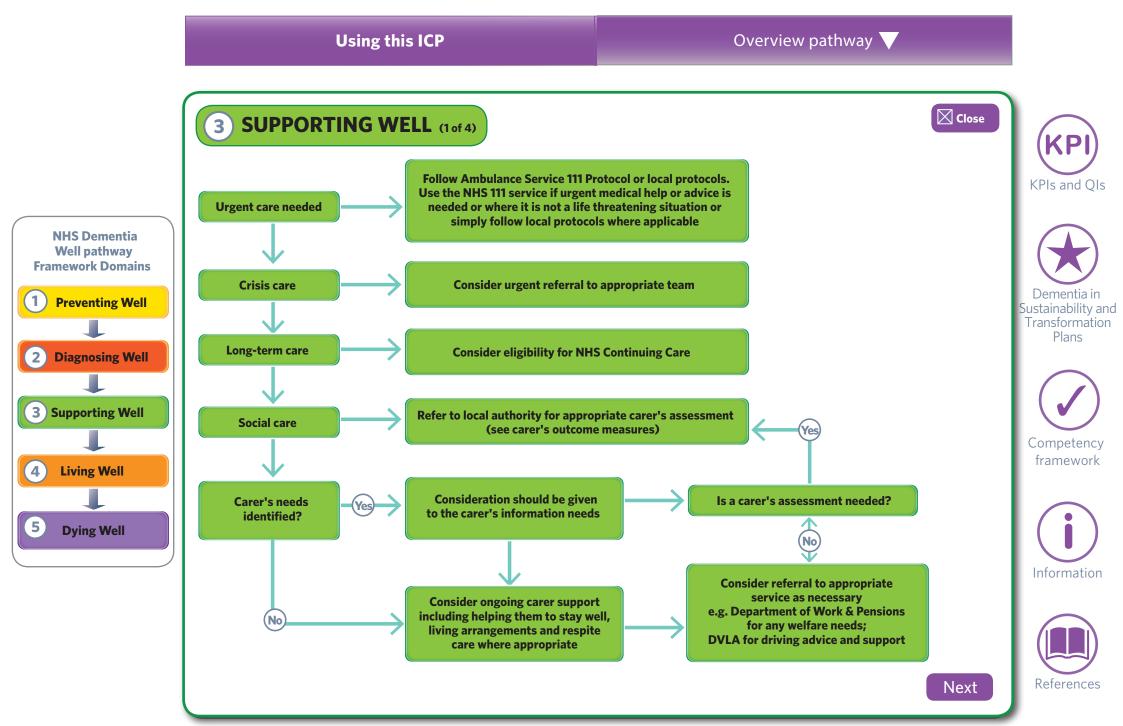












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3 SUPPORTING WELL (2 of 4)

Supporting Well Standards 9, 10, 11, 12, 13, 14 (developed by Dementia United)

- People with dementia will receive information and signposting to peer support group(s) and networks that are appropriate to their needs and preferences
- People with dementia will have their Living Well plan reviewed at least annually (or when circumstances change) including a review of medication in line with NICE guidelines
- People with dementia will be offered access to a structured group cognitive stimulation programme commissioned and
 provided by a range of health and social care workers with training and supervision, and delivered irrespective of any antidementia drug received
- Carers of people with dementia will be offered signposting and information to peer support groups that are appropriate to their needs and preferences
- Carers of people with dementia will be offered evidence-based therapies and multicomponent interventions suited to the differing circumstances of dementia carers and assessed as helpful, such as Strategies for Relatives (START)
- Carers and people with dementia will be able to access appropriate multi-disciplinary support at times of crisis through a clear, single point of contact
- Measure:

NHS Dementia

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Percentage of patients who have had their care reviewed in last 12 months (dementia)
 Source: HSCIC, Quality & Outcomes Framework, Annual (http://www.hscic.gov.uk/catalogue/PUB18887)

Consider interventions where there is evidence of positive effect for:

Reducing admissions

- Continuity of care with a GP
- · Hospital at home as an alternative to admission
- Assertive case management in mental health
- Self-management

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3 SUPPORTING WELL (3 of 4)

- Early senior review in A&E
- Multidisciplinary interventions and telemonitoring in heart failure
- Integration of primary and secondary care

Reducing re-admissions

- Structured discharge planning
- Personalised health care programmes

Source: http://www.kingsfund.org.uk/sites/files/kf/Avoiding-Hospital-Admissions-Sarah-Purdy-December2010.pdf

For urgent care:

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- The NorthWest ambulance service describes 'Urgent Care' as one where medical conditions which do not require hospital admission can be managed without a trip to an emergency department. Instead the patient could be treated using local community services or out-of-hospital facilities
- Paramedic Pathfinder: Paramedics conduct a face-to-face assessment when they arrive at the scene and, using a flow chart of specific symptoms, determine the most appropriate care pathway for that patient. Depending on the assessment, the next step for the patient could be that they are taken to either a community based specialist service, an urgent care centre or to an emergency department. If they are not in need of medical treatment, they will instead be instructed on any self-care they may need
- NHS 111 non-emergency number for accessing local health services and acts as a single point of access for urgent care and non-emergency health care. The caller will be triaged using a clinical call handling system (NHS Pathways) and the patient is subsequently signposted to a local service using a local 'Directory of Services' to most appropriately meet their need.

Source: http://www.nwas.nhs.uk/our-services/urgent-care-services/#.V_OSrE_VzIU











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3 SUPPORTING WELL (4 of 4)

Carer's assessment

- Carers have a legal right to an assessment of their needs
- Carers may require access to both practical and emotional support. It is the duty of the local authority to provide an assessment, but different services may have slightly different processes for assessment and referral
- The key point is that clinicians in Memory Assessment Services have a responsibility to identify carers, explain to them their right to an assessment, and refer on for more formal assessment and interventions where appropriate
- Carers should also be able to self-refer for an assessment.

Source: NHS Choices (2015) Carers Assessment, <u>http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/</u> <u>carers-assessment.aspx</u>

Driving

NHS Dementia

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• Driving with a diagnosis of dementia should be discussed as part of the advance care planning discussions so that people have time to think about how they will manage when they are no longer able to drive

Other considerations

- In-home help or assisted living for dementia care at home
- NHS continuing healthcare process should be considered where long-term care is required
- Meeting carer information needs for emotional support, practical support and health and wellbeing

Source: Alzheimer's society, 2013 (https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2234)

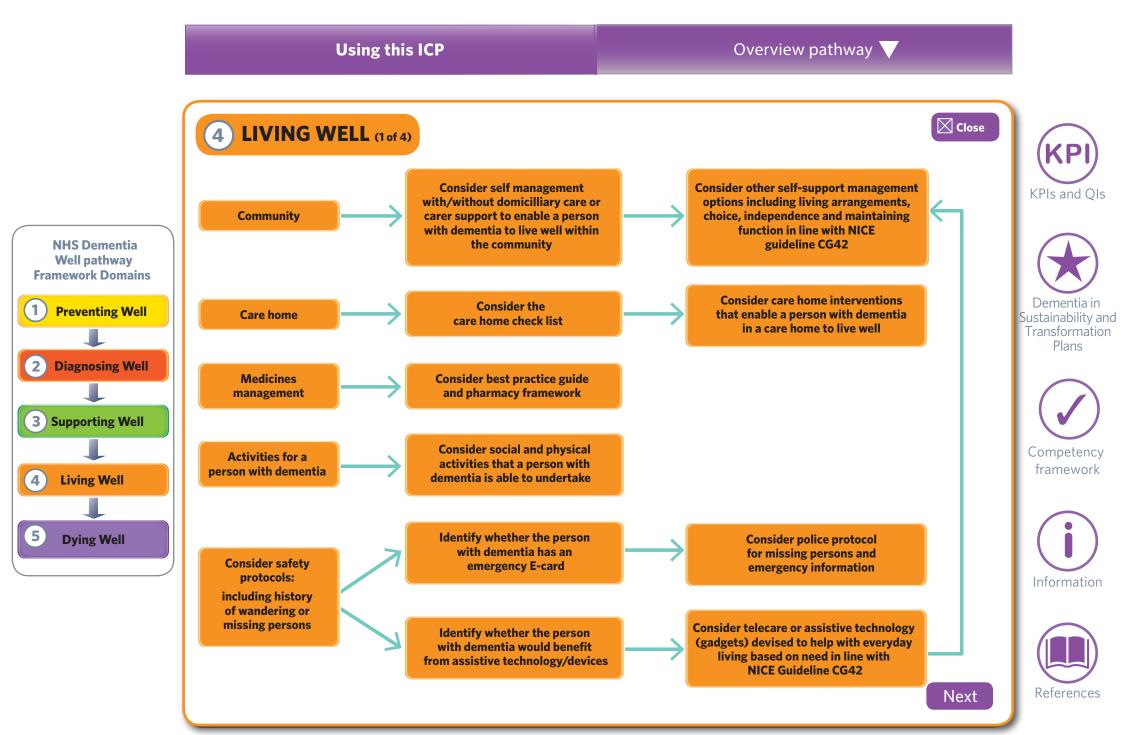












4 LIVING WELL (2 of 4)

Living Well Standards 6, 7, 8 (developed by Dementia United)

- People living with a diagnosis of dementia and their carers will be surveyed on one day per month to determine their 'lived experience'
- People with dementia should have the same access to community health and care services as others with complex support needs. Each locality will commit to monitoring a subset of community based care standards to track and evidence this
- People with dementia will receive an assessment for evidence-based assistive technology and/or necessary personal 'reasonable adjustments' shortly after diagnosis and on request by carers at other times
- Measure

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- Dementia Living Experience Barometer - Source to be developed within financial year 2017-2018

Aim

• To support people with dementia to stay at home as long as possible. This includes the provision of a range of services and support tailored to meet individual needs, including equipment, financial advice, care, activities, day services and end-of-life care

A person with dementia, their families and carers can be supported through:

- GP follow up
- Use of dementia adviser or care navigators
- Links with social care and services
- Access to peer support
- Respite care for carers in form of carers breaks & support
- Telecare
- Floating support
- Hospital care
- Intermediate care

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KPIs and OIs

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Competency framework





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- Staying Well Toolkit (developed by Bolton Council Public Health Department): 12 themes of the Quality of Life wheel:
- Health, Carer Support, Emotional Well-being, Getting out and about, Personal Care and daily tasks, House and Home, Managing Medication, Managing Money, Friends, Family and People, Communication, Volunteering and Work, Hobbies and Interests

Link: Staying Well

Nice Guideline CG42: Essential recommendations

- Care plans for promoting independence and maintaining function should address activities of daily living (ADL) that maximise independent activity, enhance function, adapt and develop skills and minimise need for support
- Should also address the varying needs of people with different types of dementia

Consider social prescribing: see Health Education England directory

NICE Guideline CG42 recommends:

- Physical exercise, with assessment and advice from a physiotherapist when needed
- Support for people to go at their own pace and take part in activities they enjoy

Resources developed by Greater Manchester Police include:

- Herbert Protocol
- Dementia Guardian Angel

Examples of how assistive technology and telecare can help a person with dementia to live well in the community:

- Reminder to take their medication at the right time
- Locate lost items
- Orientation around day time or night time
- Assistance to phone relatives or friends
- Using pre-programmed numbers or pictures
- Reminders not to open the door for strangers

NHS Dementia Well pathway Framework Domains 1 Preventing Well 2 Diagnosing Well 3 Supporting Well 4 Living Well 5 Dying Well

4 LIVING WELL (4 of 4)

- Switch on the lights automatically if the person gets up at night time
- Alerting a carer or monitoring centre that the person needs assistance
- Telecare may also help to support and reassure carers, e.g. it may enable a carer to get a good night's rest, knowing that if the person gets up at night they will be alerted

NICE Guideline recommends:

• Environmental modifications to aid independence, including assistive technology, with advice from an occupational therapist and/or clinical psychologist

Source: Supporting people with dementia and their carers in health and social care, NICE guideline CG42

Considerations for community and care home interventions may include:

- Self-management/domicilliary care, social prescribing, medicines management, managing frailty (falls), long-term conditions, managing co-morbidities, timely reviews within care homes by care home managers, carer support
- Access to geriatrician /neurologist / specialist dementia and mental health services / community psychiatric nurse

Consider referral to dementia community support groups to:

Enhance peer support, enhance community participation, reduce social isolation, raise awareness of dementia and tackle stigma, referral/signposting to dementia support groups, enhance dementia friendly communities

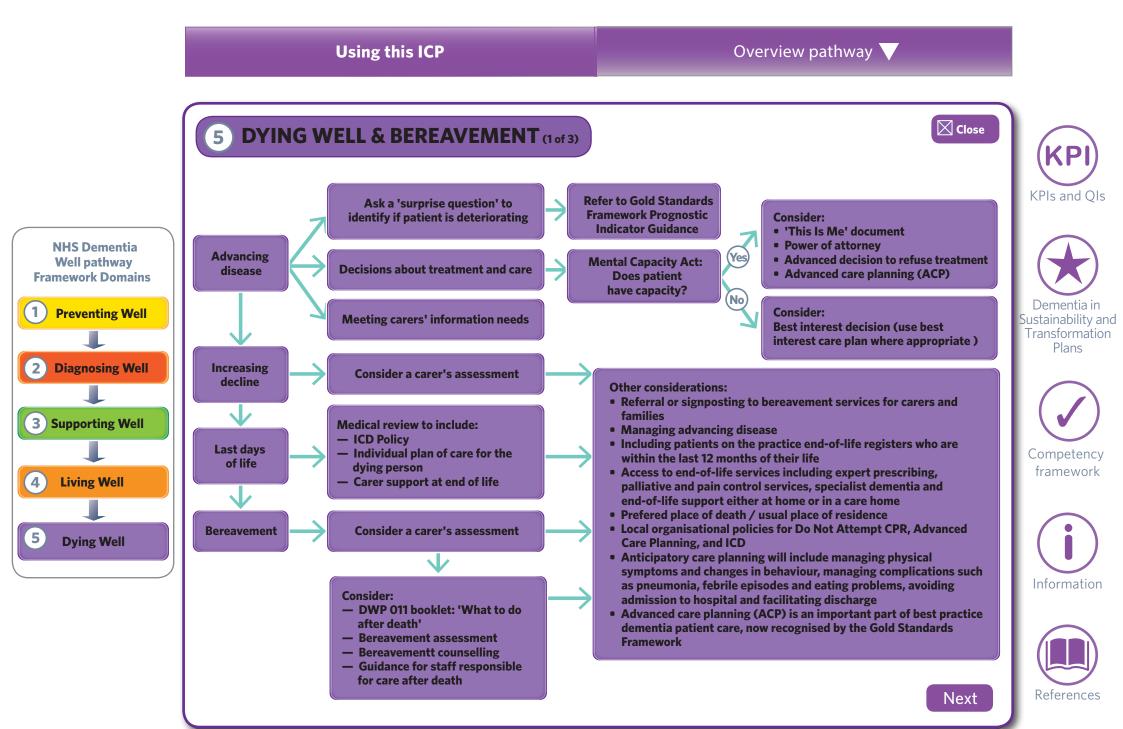












DYING WELL & BEREAVEMENT (2 of 3) 5

Dying Well Standards 15 (developed by Dementia United)

- All people with a diagnosis of dementia will have a preferred place of death recorded in their care record
- Measure:
- Preferred place of death recorded in care record (Source: HSCIC, Primary Care Mortality Dataset)

Best practice for end-of-life care in dementia

- Effective communication skills
- Do not attempt CPR
- Advocacy
- Advanced care planning (ACP)
- Anticipatory care planning
- Preferred place of death /death in usual place of residence (DIUPR)
- Education and better understanding of the condition can help staff support better patient care towards end-of-life by enabling the right conversations with patients, their carers and families and providing contextually appropriate care based on individual needs

Gold Standards Framework Prognostic Indicator Guidance for dementia:

Things to look out for that are indicative of someone entering a later stage of dementia (advancing disease):

- Unable to work without assistance
- Urinary and faecal incontinence
- No consistently meaningful conversation
- Unable to do activities of daily living (ADL)
- Barthel score <3

Preventing Well Diagnosing Well



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5 DYING WELL & BEREAVEMENT (3of 3)

Plus any of the following:

- Weight loss
- Urinary tract infection
- Severe pressure sores, stage 3 or 4
- Recurrent fever
- Reduced oral intake
- Aspiration pneumonia

Best interests checklist considerations

The Mental Capacity Act gives a checklist of things to take into account when making a decision for someone who lacks capacity or for carrying out an act on their behalf:

- Encourage the person to take part as much as possible
- Identify all relevant circumstances
- Find out the person's past and present wishes, feelings, beliefs, values and any other factors they would be likely to consider if they had capacity, including any advanced statements
- Do not make assumptions based on the person's age, appearance, condition or behaviour
- Assess whether the person might regain capacity
- If the decision concerns life-sustaining treatment then the best interests decision should not be motivated by the desire to bring about the person's death
- Consult with others where it is practical and appropriate to do so. This includes anyone previously named as someone to be consulted; anyone engaged in caring for the person; close friends, relatives or others with an interest in the person's welfare; any attorney and any deputy appointed by the court
- Avoid restricting the person's rights by using the least restrictive option
- Abide by any valid advanced decision

Source: http://cms.walsall.gov.uk/index/mentalcapacityact-bestinterestsandchecklist-2.htm

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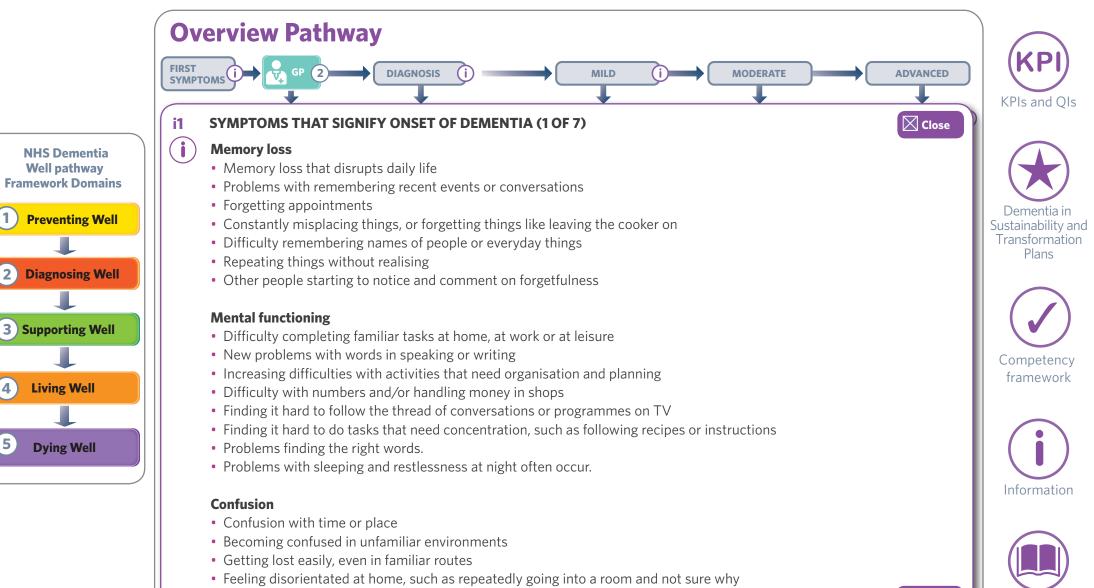












Poor judgement in making decisions, for example managing finances

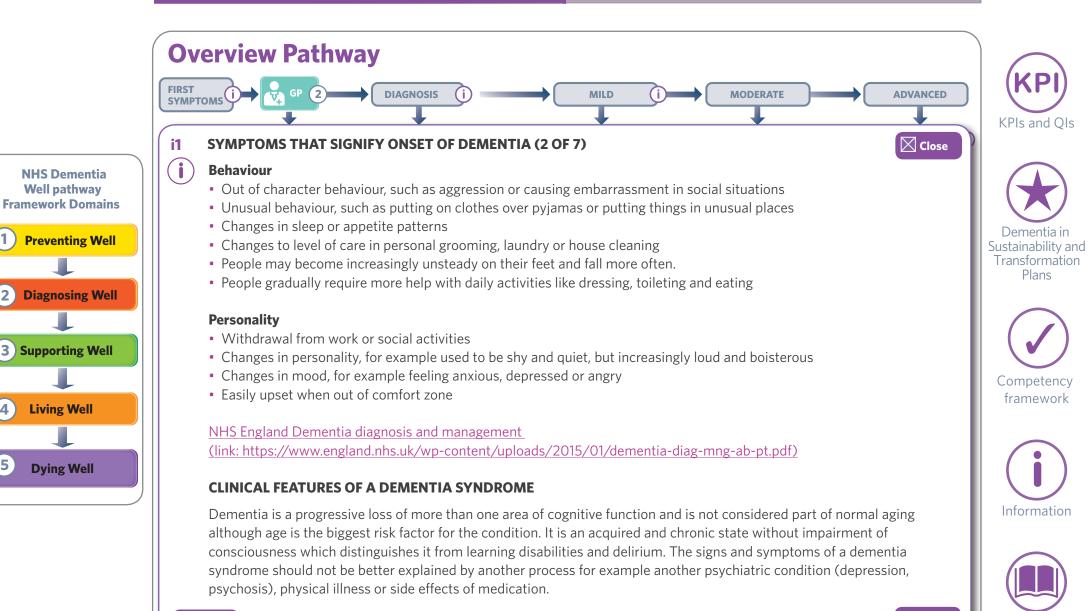
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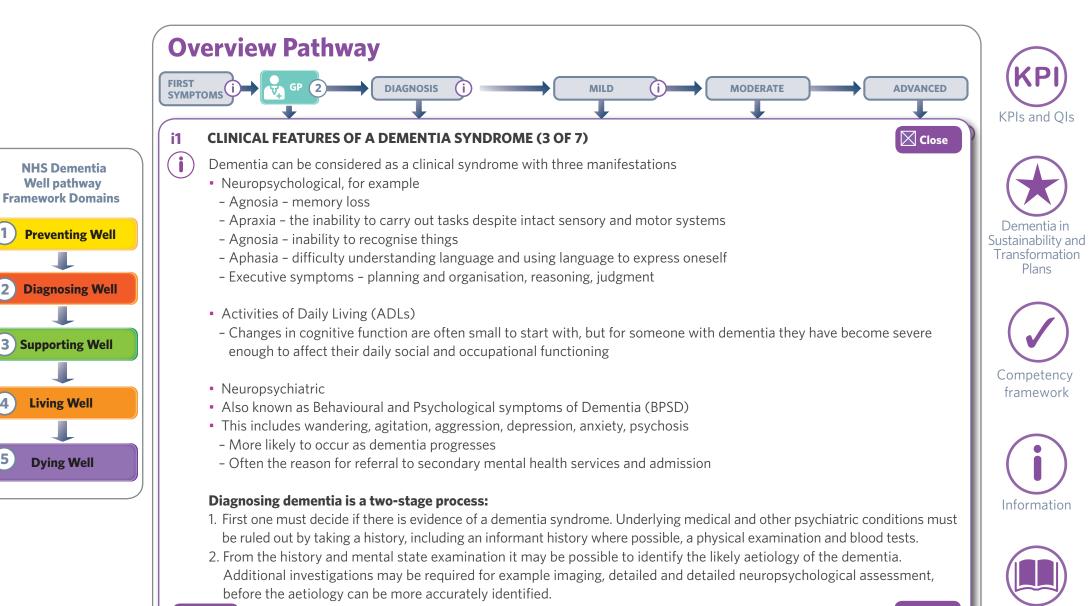
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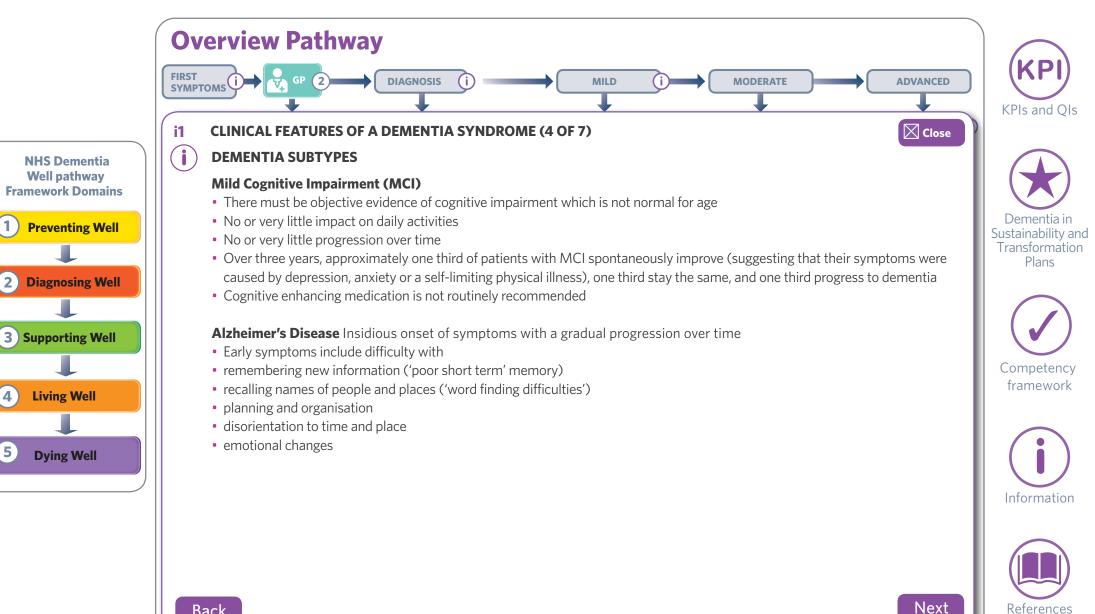
Living Well

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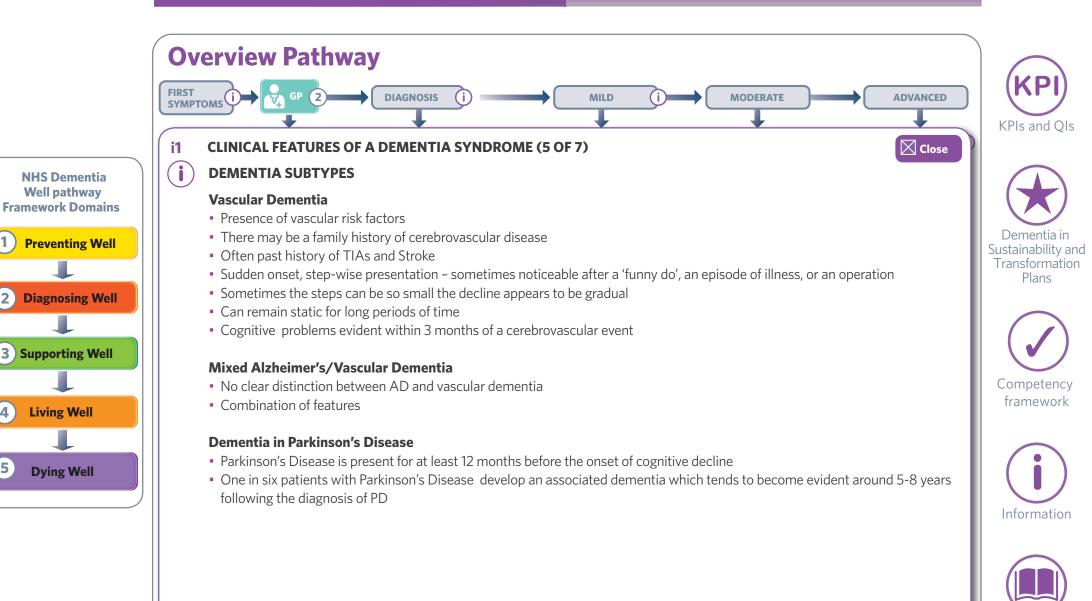
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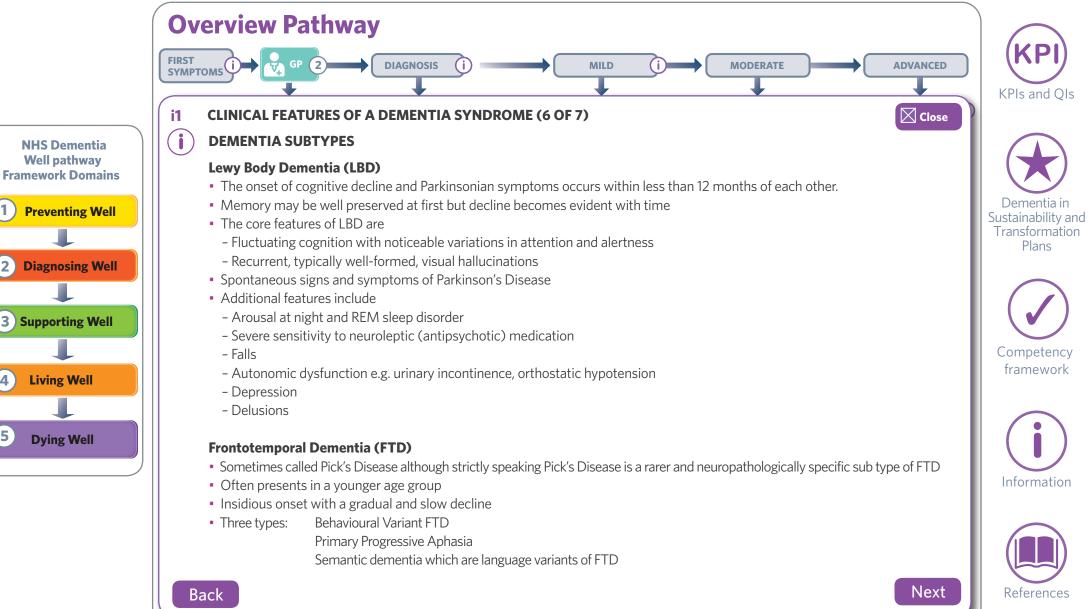




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Living Well

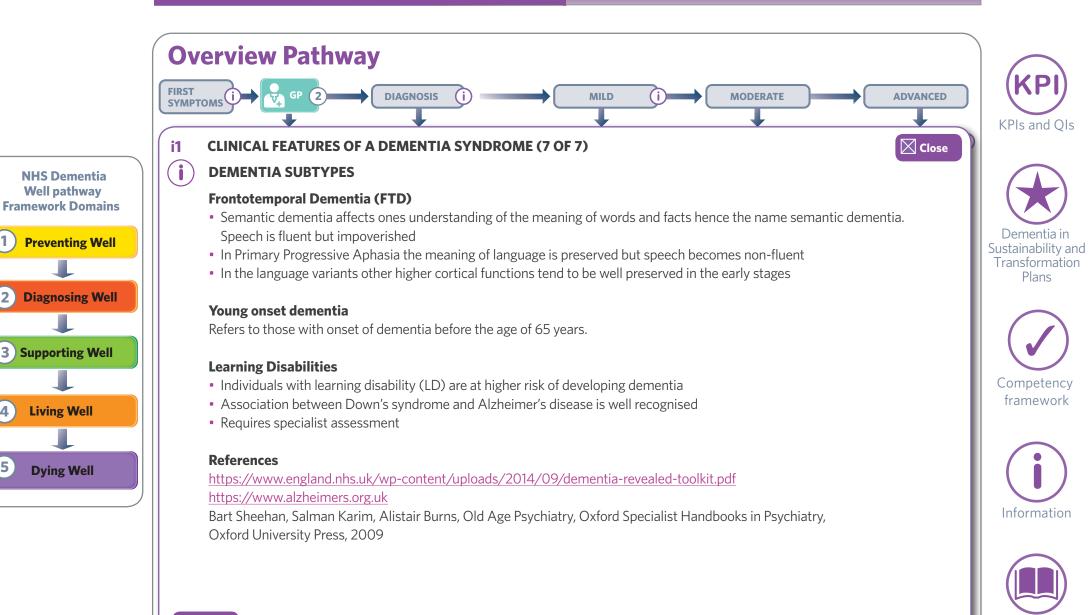
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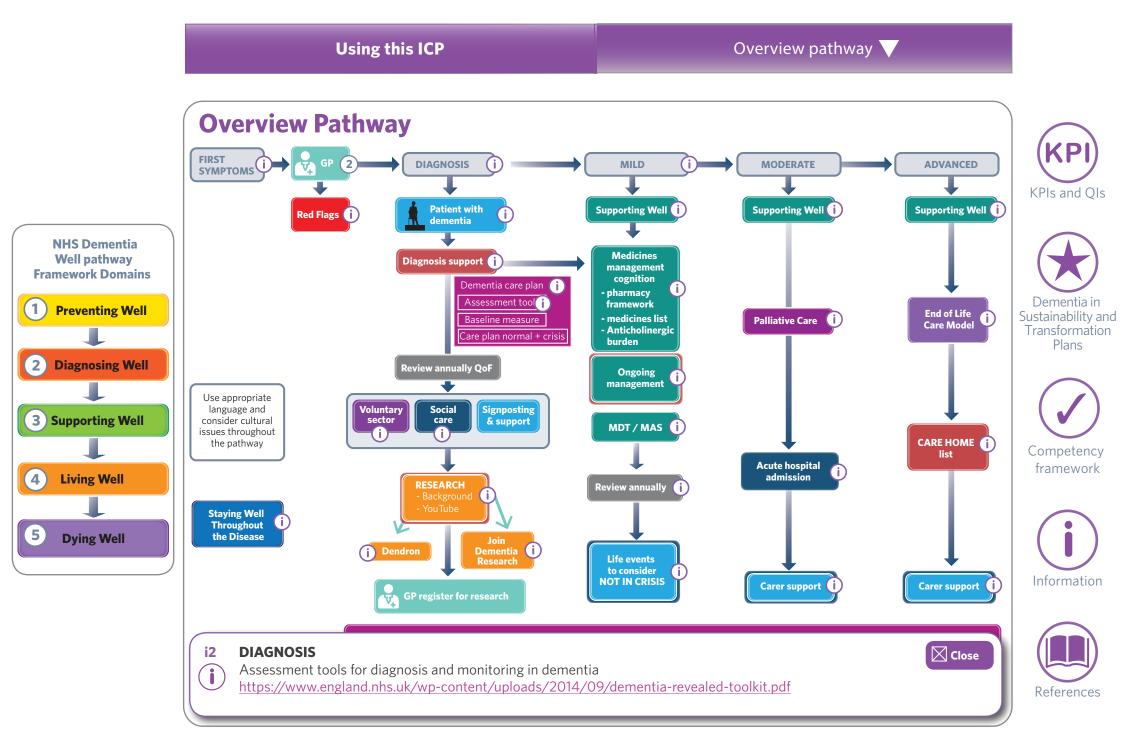
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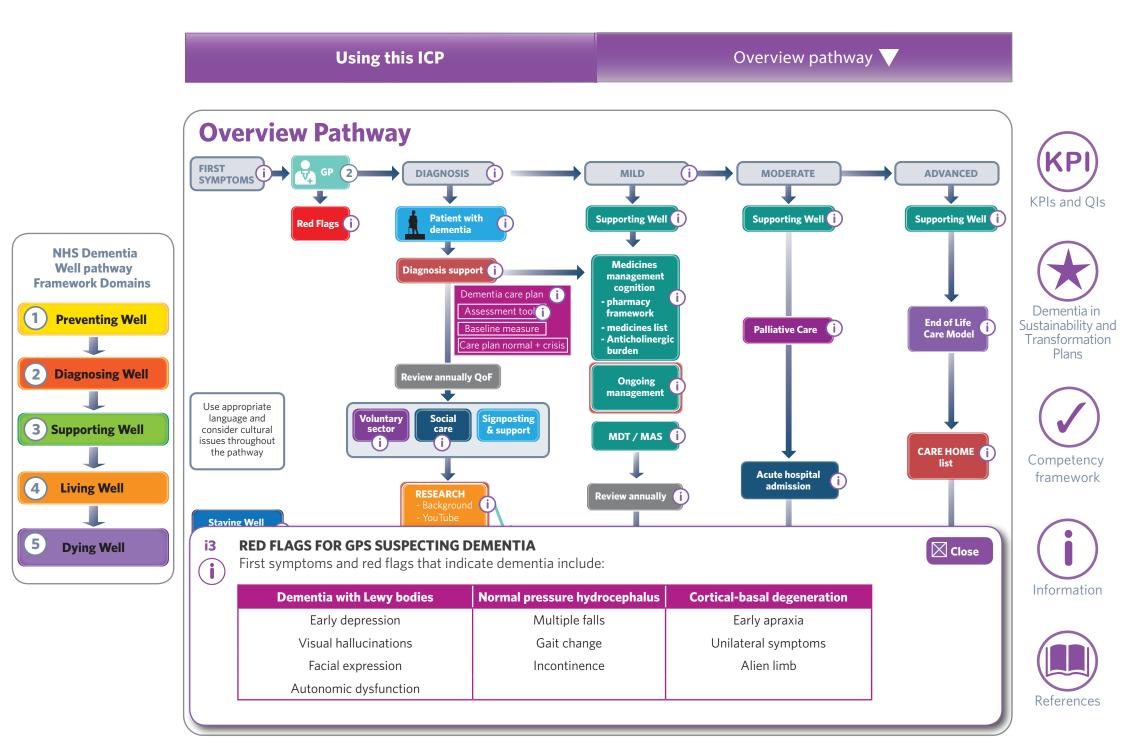
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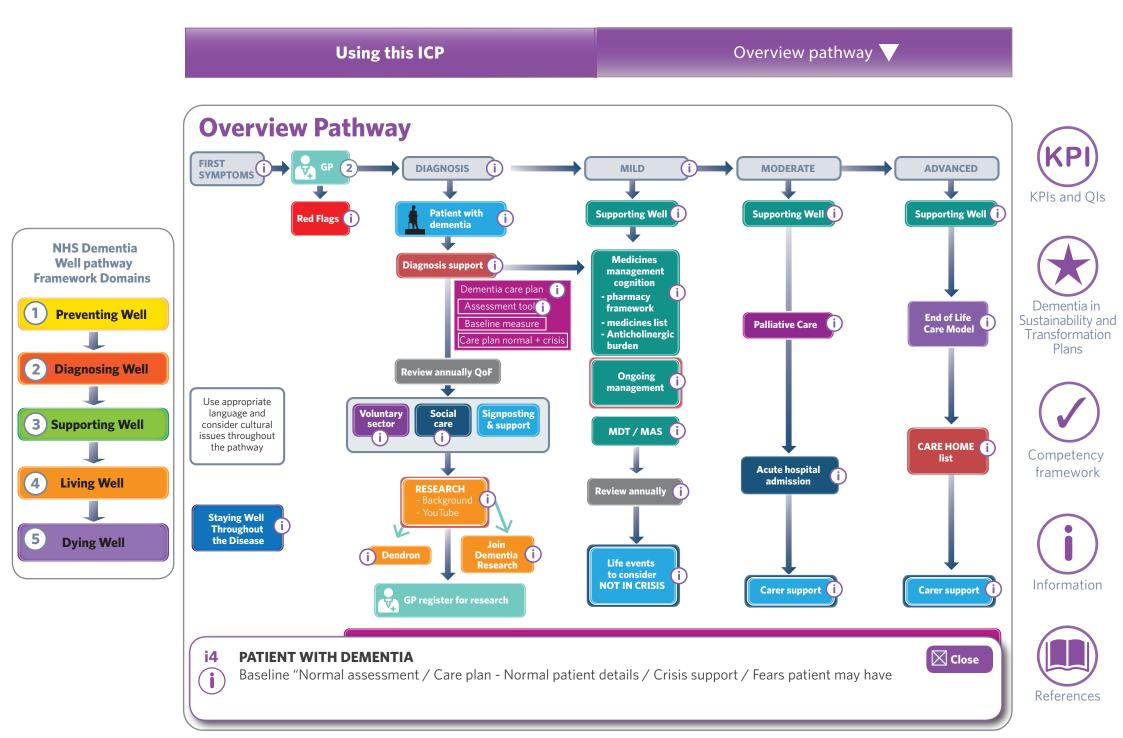


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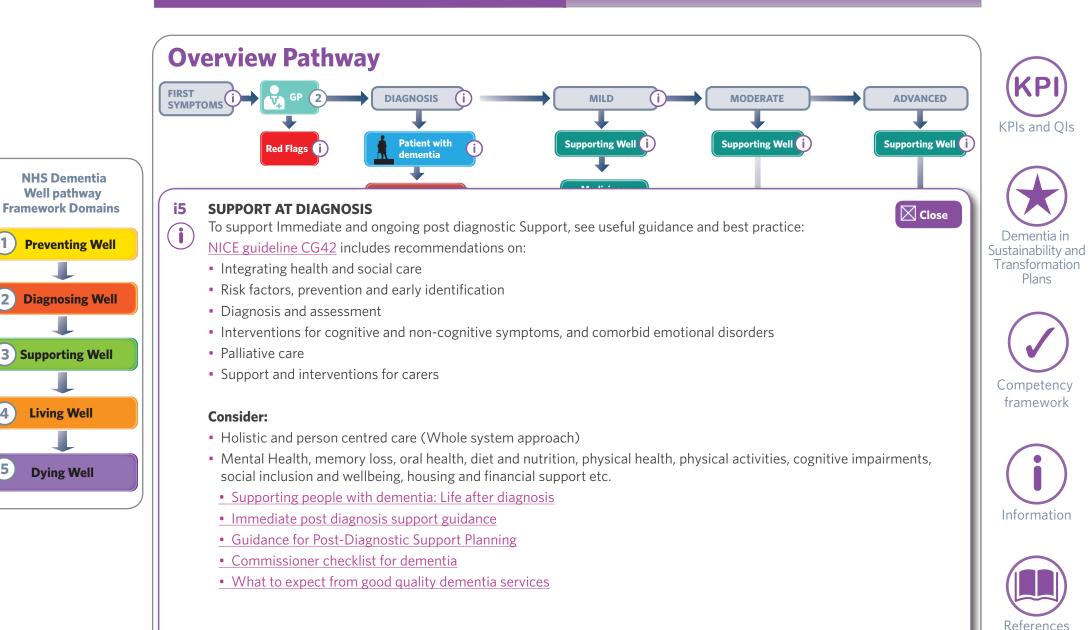


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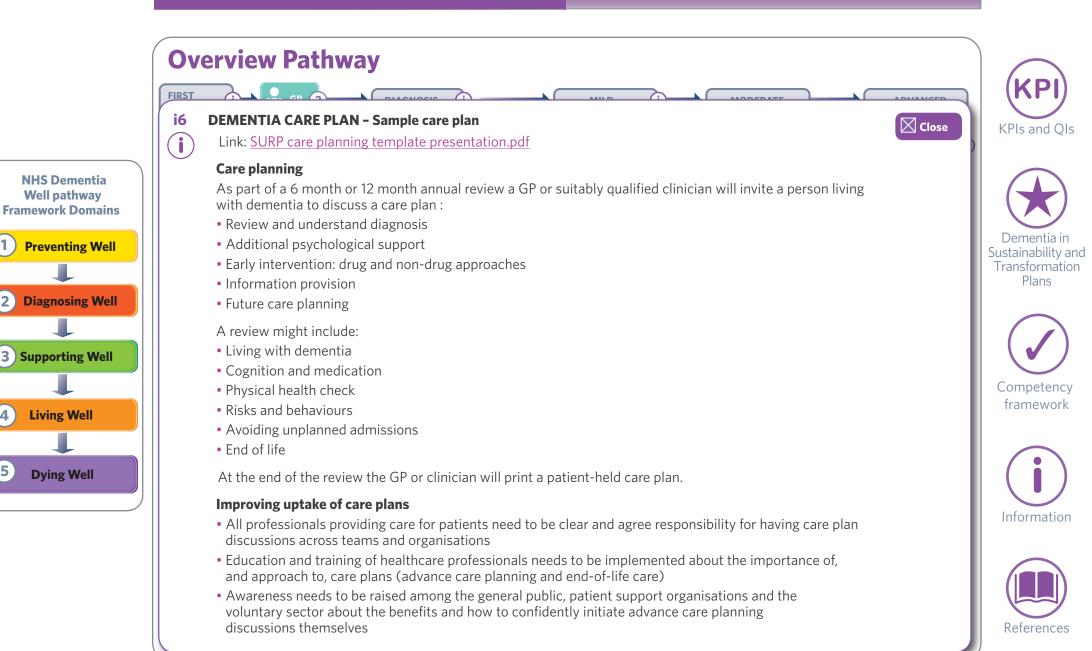


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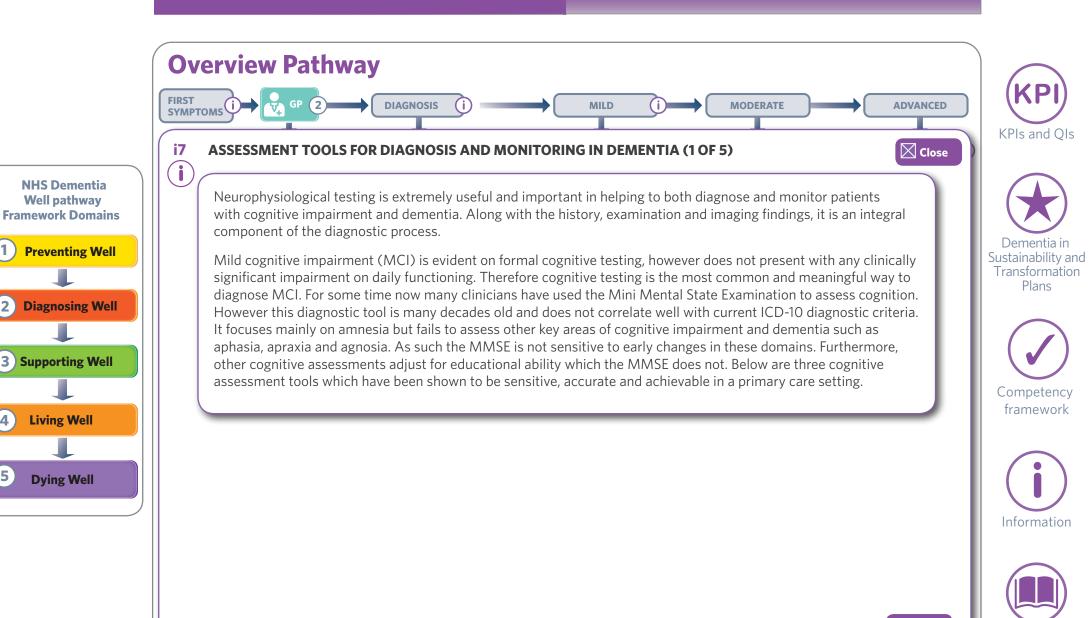


Living Well

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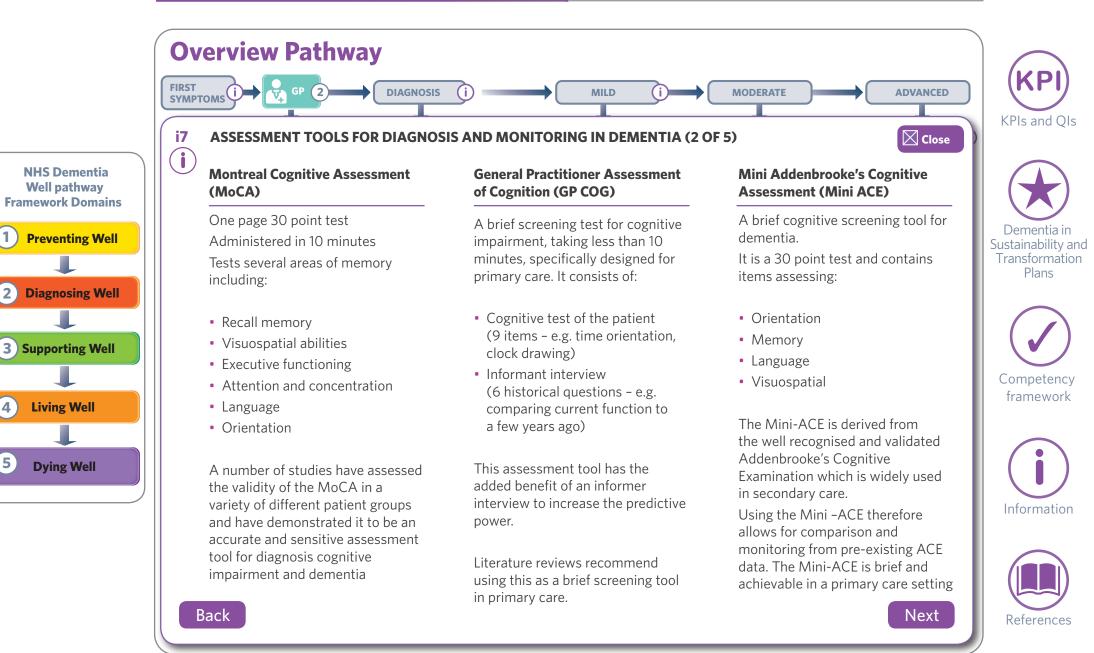
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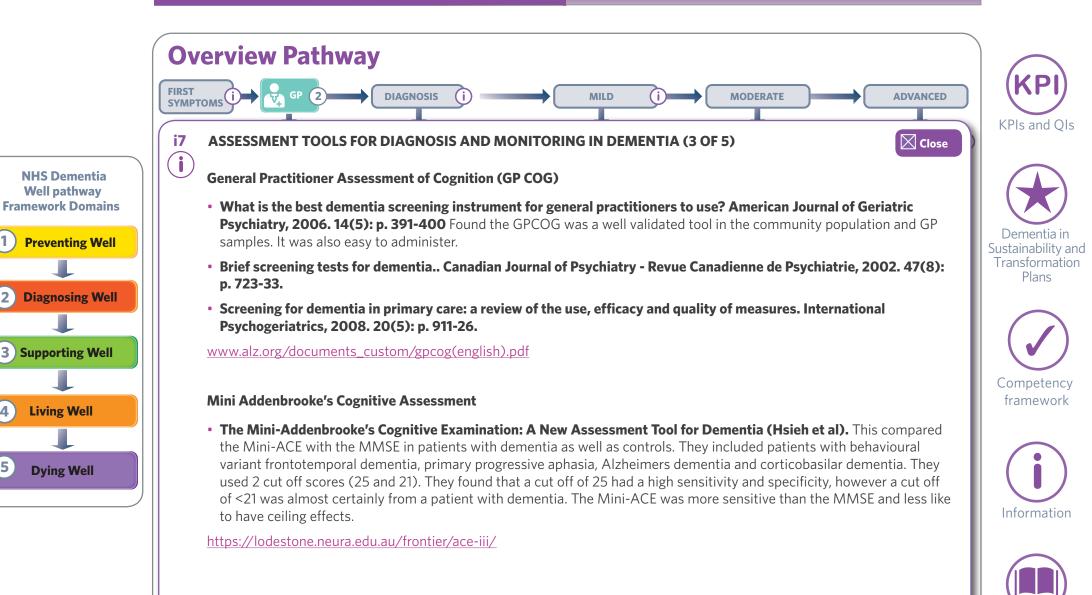
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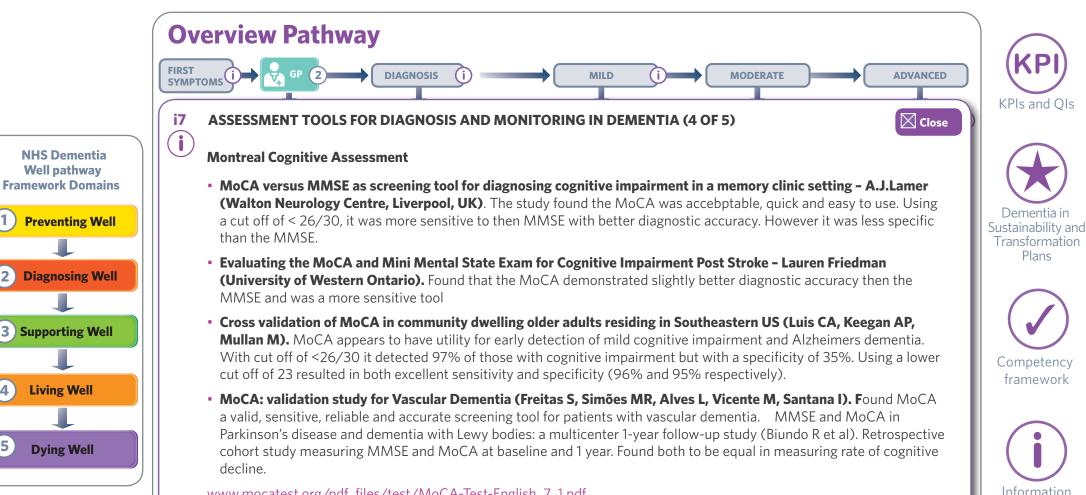


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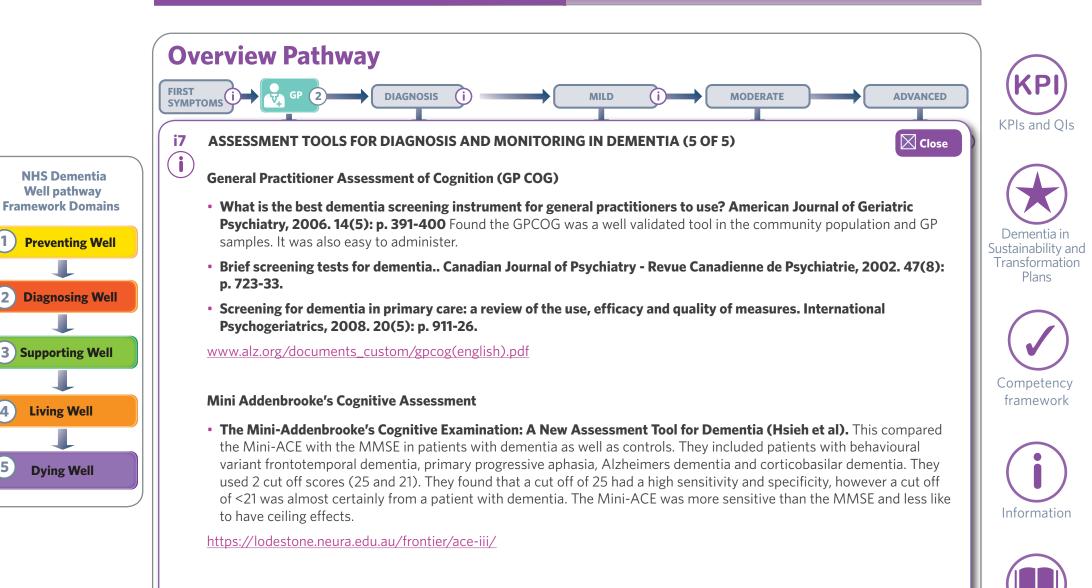
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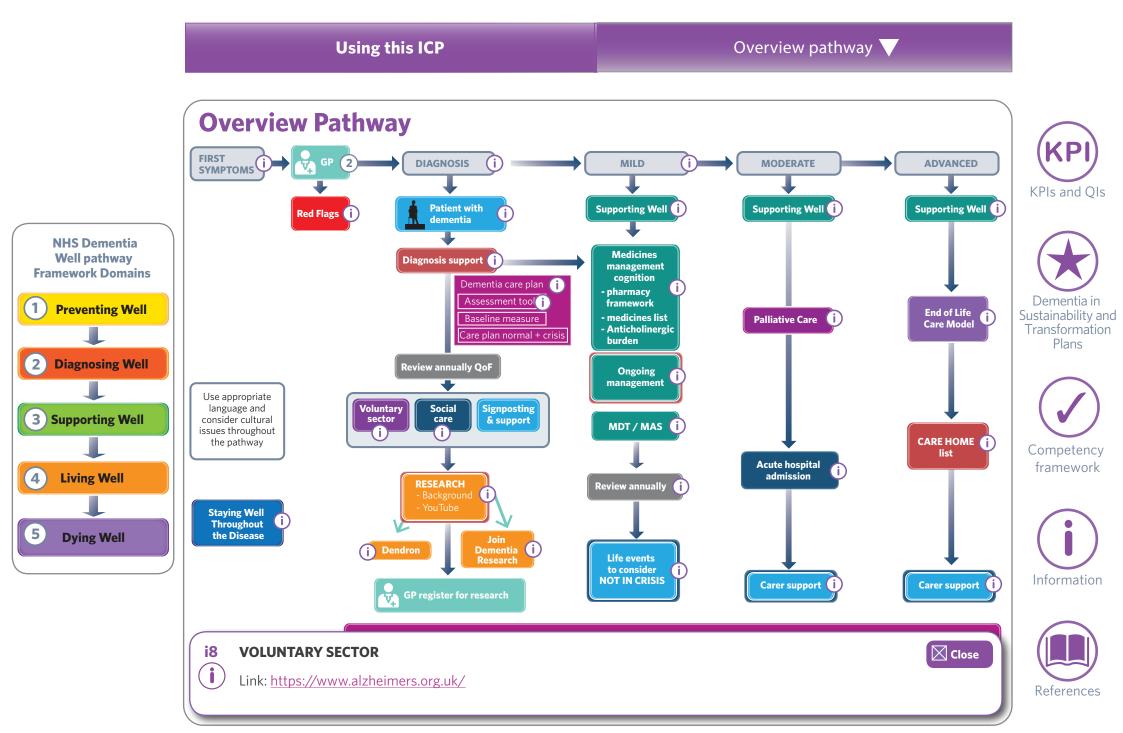
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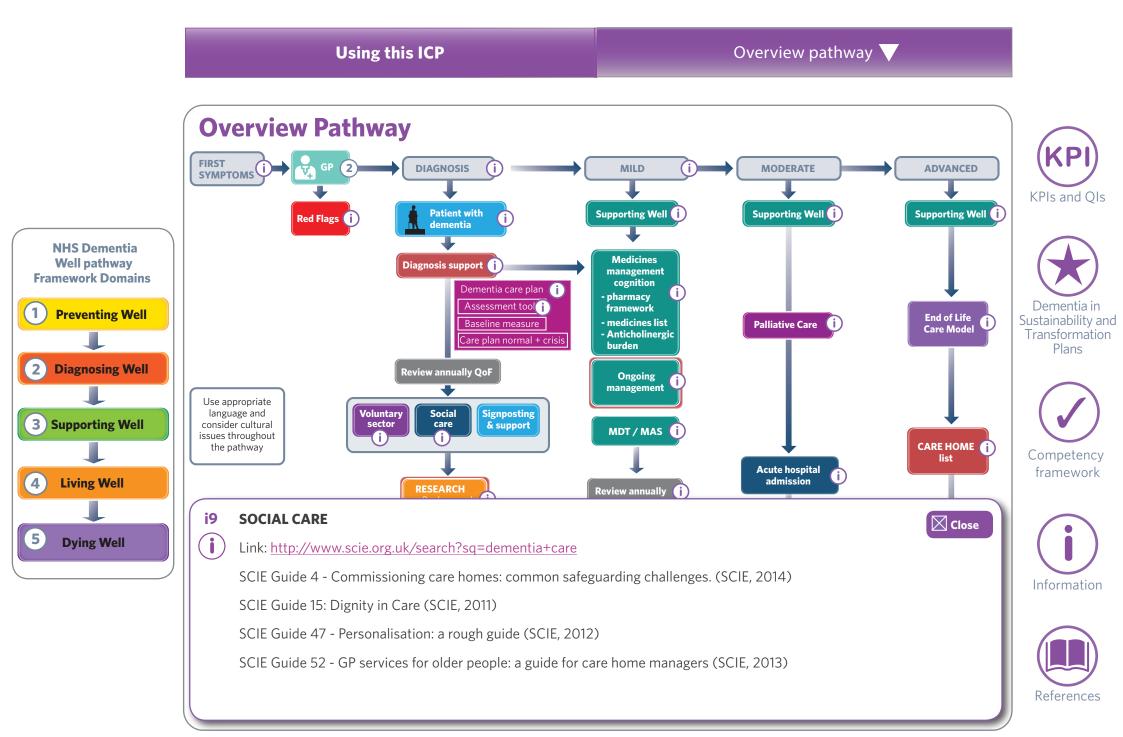
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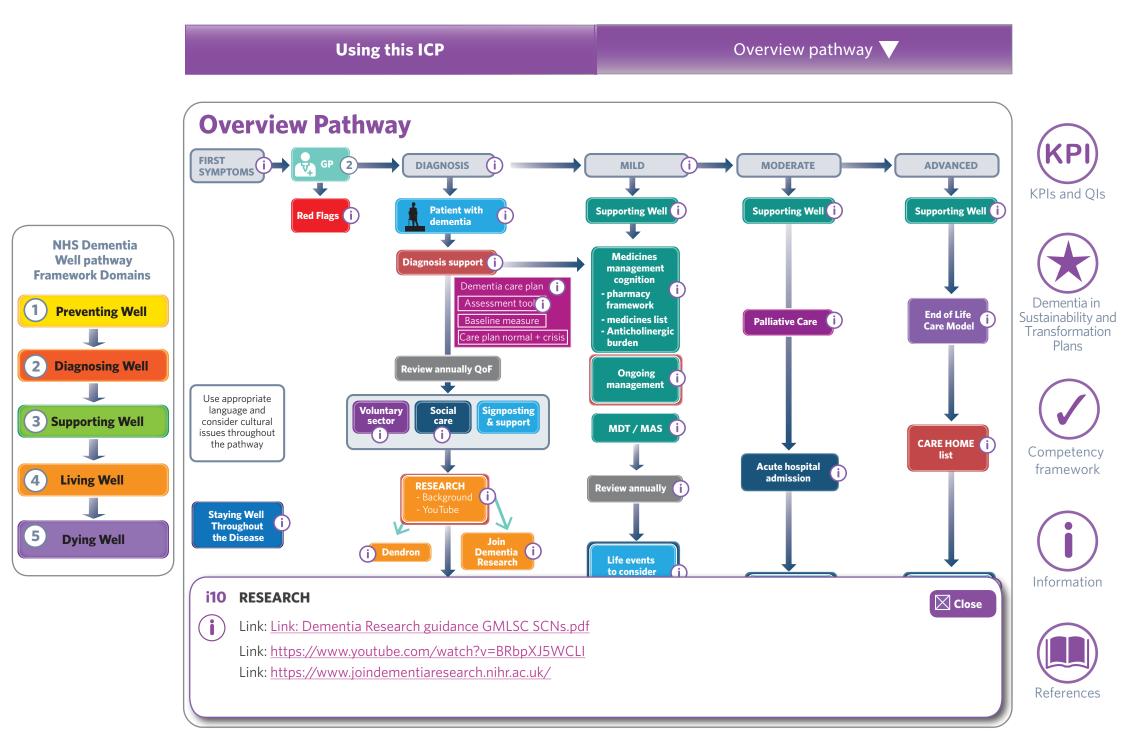


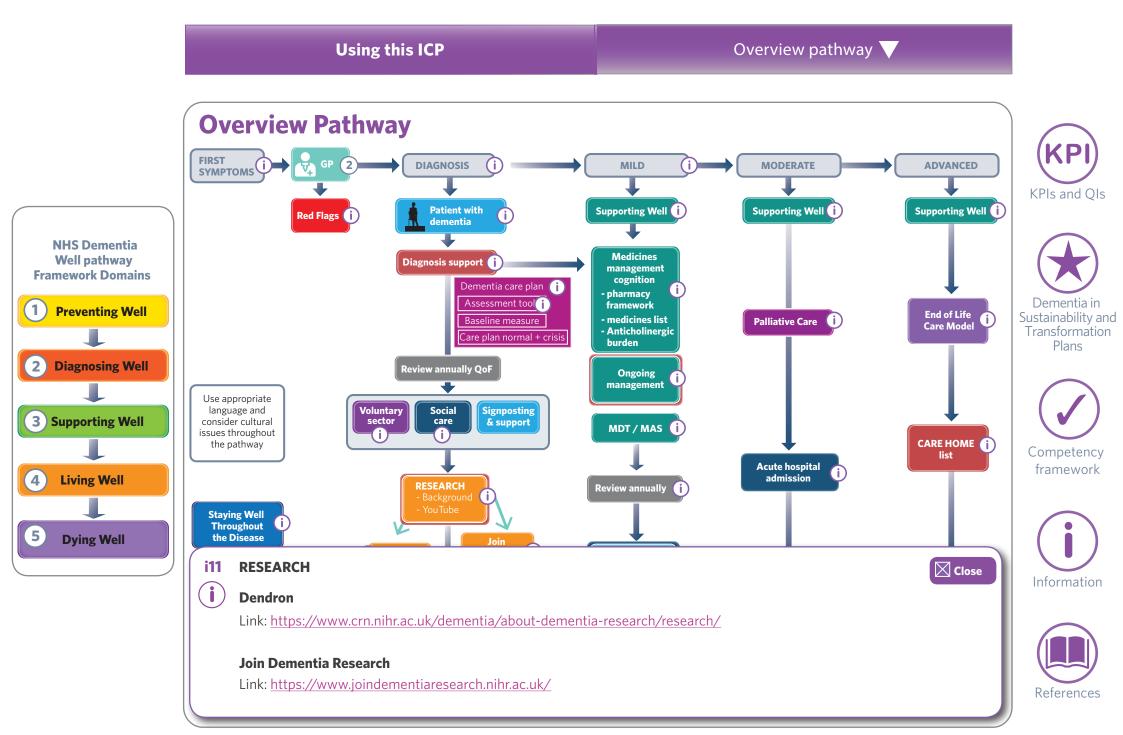


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	Acetylcholinesterase inhibitors (Achi)			NMDA antagonist	
Medication	Donepezil	Rivastigmine	Galantamine	Memantine	
Mode of Action	Increases concentration of acetylcholine which improve communication between nerve cells.		Neuroprotective effect by blocking excess glutamate which can damage cells.		
Benefits	Medications do NOT slow the progression of Alzheimer's disease. They provide treatment of symptoms, and improvement is seen in 40-70% of people. This may include reduction in levels of anxiety, improvement in motivation, memory, concentration and improved ability to continue activities of daily living.			Evidence in reducing delusions, agitation and aggression	
When to start		cognitive, global, function ents with mild to modera		For treatment of symptoms in people with severe Alzheimer's disease OR Moderate Alzheimer's disease who are intolerant or have contraindication to Achi.	
How to start	Carer's view on patient's condition at baseline to be sought. To be initiated by specialists in care of patients with dementia. To be gradually increased over months as detailed below.				
When to stop	Evidence of poor compliance with no available strategies to improve compliance. Careful consideration of benefits and risks. Treatment should stopped when it is considered that it is no longer having a worthwhile effect on cognitive, global functional or behavioural symptoms and decision should be made in consultation with patient and/or carer.				
How to stop	To taper and stop gradually over 4 week. Patient should be observed for any changes in cognition, function or behaviour.				









References



	Acetylcholinesterase inhibitors (Achi)			NMDA antagonist
Medication	Donepezil	Rivastigmine	Galantamine	Memantine
Form	Tablets Orodispersible tablets	Capsules, Oral solution Transdermal patches	Tablets, Oral solution Modified release (MR)	Tablets, Oral solution
Dose	5mg mane for 4 weeks Increase to 10mg mane	 1.5mg bd for 2 weeks Increase to 3mg bd for 2 wks Maximum 6mg bd Transdermal 4.6mg/24 hours for 4 weeks 9.5mg/24 hours for 6 mths Max 13.3mg/24 hours If treatment interrupted for more than 3 days retitration required 	4mg bd for 4 weeks Increase to 8mg bd for 4wks Max 8-12mg bd MR preparation 8mg od for 4 weeks Inc to 16 mg od Max 16-24mg od	5mg od for 1 week Increase to 10 mg for 1 week Increase to 15mg for 1 week Max 20mg od
Side effects	Gastrointestinal: abdo pain, dyspepsia, nausea vomiting, diarrhoea, anorexia weight loss Cardiac: Arrhythmias, hypotension Neurological: headache, dizziness, fatigue, insomnia, seizures Others: Urinary incontinence, muscle spasm			Constipation raised blood pressure Headaches, dizziness, fatigue
Rare side effects	Peptic ulcers, seizures, rash, Hepatitis, pancreatitis, bladder outflow obstruction, blurred vision, blurred vision, taste disturbance; tinnitus, hallucinations			Abnormal gait; confusion, hallucinations; heart failure; thrombosis; vomiting, seizures
Cautions	Hx of Asthma, COPI	D, cardiac conduction abnormalities, p	eptic ulcers, seizures.	Hx of seizures

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NHS Dementia Well pathway **Framework Domains**

Preventing Well

Diagnosing Well

3 Supporting Well

Living Well

Dying Well

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References

KPIs and OIs

Dementia in Sustainability and Transformation Plans







Alternative Treatments **Drugs with anti-cholinergic properties** Indication Oxybutynin Urinary incontinence Trospium Tolterodine Darifenacin Metoclopramide Nausea Ondansetron Cvclizine Prochlorperazine Amitriptvline Depression SSRIs Nortriptyline Trial without (only 10% of long-Procyclidine To counteract extra-pyramidal side effects term uses need to re-start) Hyoscine hydrobromide Hyper-salivation Pirenzepine Chlorphenamine Antihistamines Loratadine Promethazine Fexofenadine Hydroxyzine Cvclizine Ranitidine Gastritis etc. Omeprazole Cimetidine Lansoprazole Chlorpromazine Psychosis/anxiety Quetiapine Promazine

i12 ANTICHOLINERGIC BURDEN (ACB) (3 OF 3)

Back

Acetylcholine has a role in memory function, attention and new learning. Drugs with anticholinergic properties can have several adverse effects including sedation, cognitive impairment, falls and delirium. These effects may be worse for people with dementia. The concomitant use of drugs with anticholinergic properties increases the anticholinergic burden (ACB).

Overview pathway 🗸

ACB Scales are a practical tool to establish the ACB of the medications that a patient is prescribed and should be used routinely to inform prescribing choices and reduce the risk of harm.

A high score on an ACB scale is associated with acceleration in cognitive decline and increased mortality. It is important to calculate the ACB for patients using a recognised ACB scale and adjust medications to keep their ACB to a minimum.

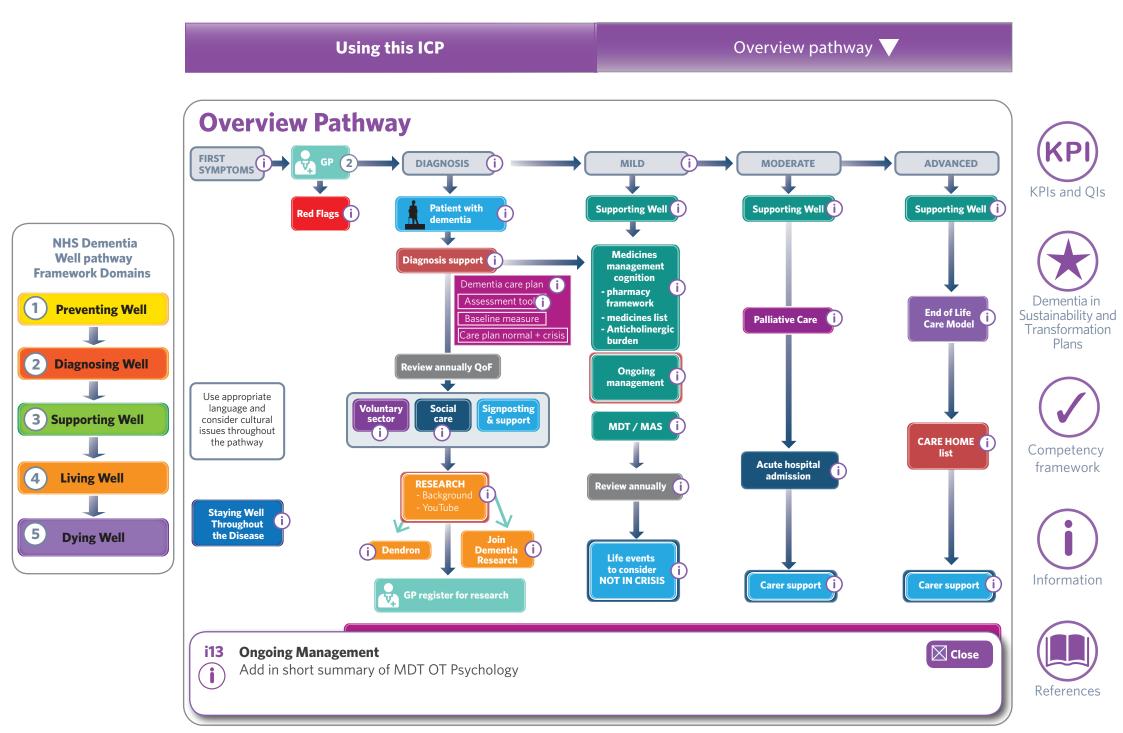
Wherever possible drugs should be chosen which have an equivalent therapeutic effect but a low, or nil, cholinergic burden. If this is not possible then anticholinergic drugs that do not cross the blood-brain barrier are preferred as they are likely to have a significant effect on cognitive function.

In the table below alternative treatments are suggested as alternatives to treatments that have a high ACB

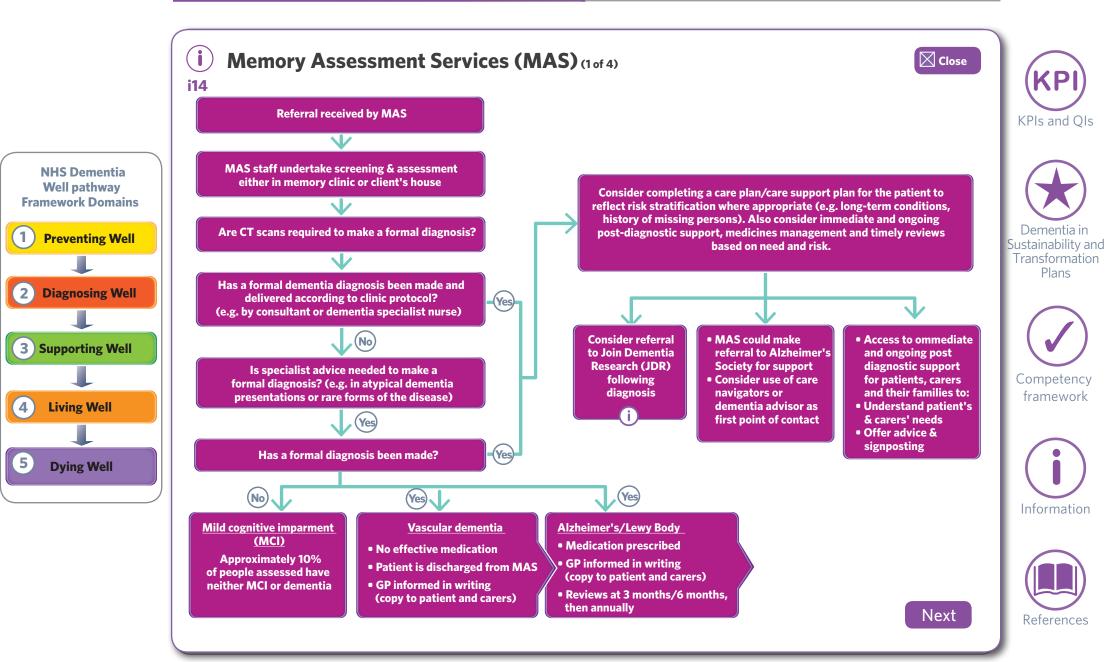


NHS Dementia

Well pathway



Overview pathway 🗸





Overview Pathway

Service Specification for Memory Assessment Services (MAS) (2 of 4) i14

The MAS should be able to:

- Offer home-based assessment when requested
- Give pre- and post-diagnostic counselling
- Make the diagnosis of dementia accessing specialist psychometric assessments and timely brain imaging where necessary
- Explain the diagnosis
- Give information about the likely prognosis and options for care
- Provide advice and support
- Provide pharmacological treatment of dementia
- Follow-up and review.

Source: https://www.england.nhs.uk/

Making a diagnosis in MAS

- Any clinician who has the appropriate skills can recognise and make a diagnosis of dementia, once it is established.
- Specialist advice may be needed in the very early stages and in particular clinical situations such as when the presentation or course is atypical, where significant risks are identified and in groups such as people with learning disabilities
- Specialist advice may also be needed to establish the exact cause of the dementia
- Following a specialist diagnosis, information which will include; diagnosis, Read code, clarity on diagnosis, clarity on responsibility for diagnosis and identification of the carer should be made
- For links to other services suggestions from MAS for GP referral to stroke clinic or vascular services Source: https://www.england.nhs.uk/2014/11/skills-to-recognise-dementia/

CT scanning and the impact on diagnosis

- CT scans may/may not be required for diagnosis (could delay diagnosis)
- NICE dementia guideline states that "Imaging may not always be needed in those presenting with moderate to severe dementia, if the diagnosis is already clear.

Source: https://www.england.nhs.uk/2014/11/skills-to-recognise-dementia/











Information

References



Overview Pathway Service Specification for Memory Assessment Services (MAS) (3 of 4) i14 **Mild Cognitive Impairment (MCI)** KPIs and OIs People diagnosed with MCI (including those without memory impairment, which may be absent in the earlier stages of non-Alzheimer's dementia) should be offered follow-up to monitor cognitive decline and other signs of possible dementia in order to plan care at an early stage (NICE 2006) • People with MCI should be offered assessment and management of cardiovascular risk factors. Primary care assessment of cardiovascular risk factor is appropriate People with MCI should be offered annual review including cognitive assessment • For patients with MCI - If single-domain, most are discharged back to GP, if multi-domain e.g. family history of dementia, Memory Assessment Services to follow up Source: West Lancashire Dementia pathway (https://www.england.nhs.uk/2014/11/skills-to-recognise-dementia/) Best practice and tips for medicines management (see NICE guidance CG42 for more information) • Carry out a review of existing medications either with or by primary care to avoid clinical risks. This is especially important for those drugs which could have an adverse effect on cognitive function; for example opiates, anticholinergic drugs, sedative antihistamines and tricyclic antidepressants. It is essential that arrangements are made for future reviews where appropriate

- Where appropriate, discuss the use of dementia drugs with the patient and carer. An appropriate risk assessment should be conducted prior to initiation of medication. Clinicians should follow NICE guidance to select an appropriate treatment. The patient and carer should be provided with written information
- NICE guidance states that the most cost-effective drug should be tried first

Other Considerations for Memory assessment services (MAS)

- Patient with Mild Cognitive Impairment
- If single-domain, most are discharged back to GP
- If multi-domain e.g. family history of dementia, Memory assessment services to follow up



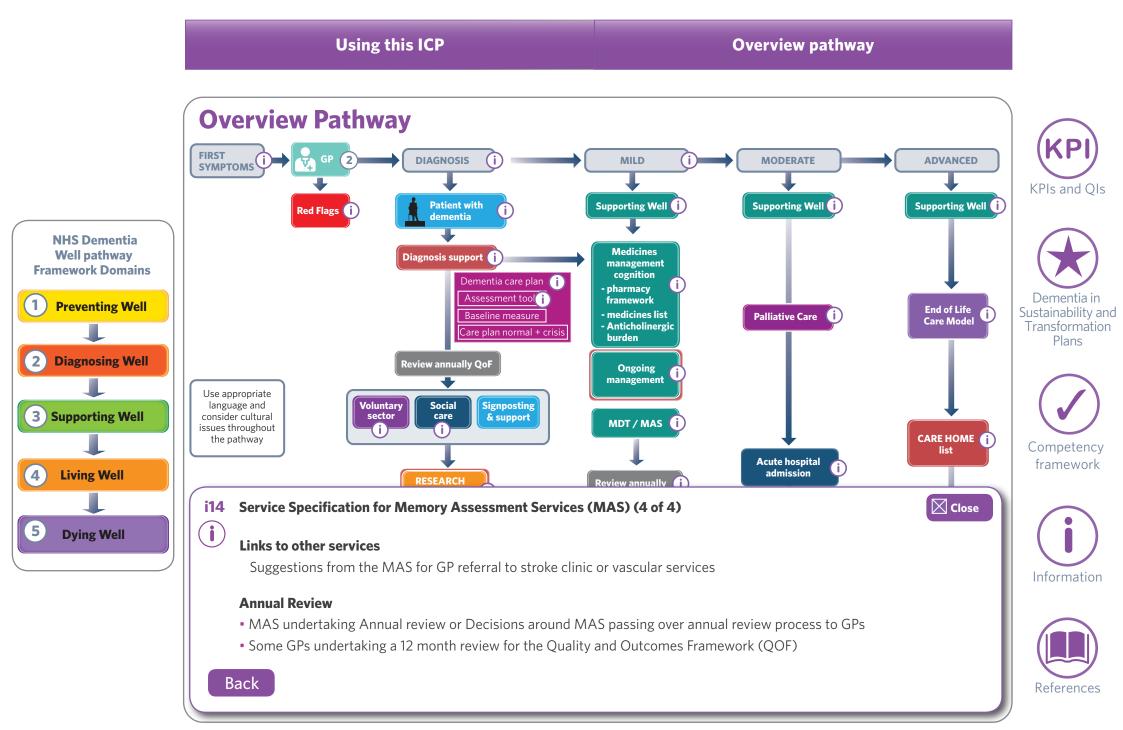












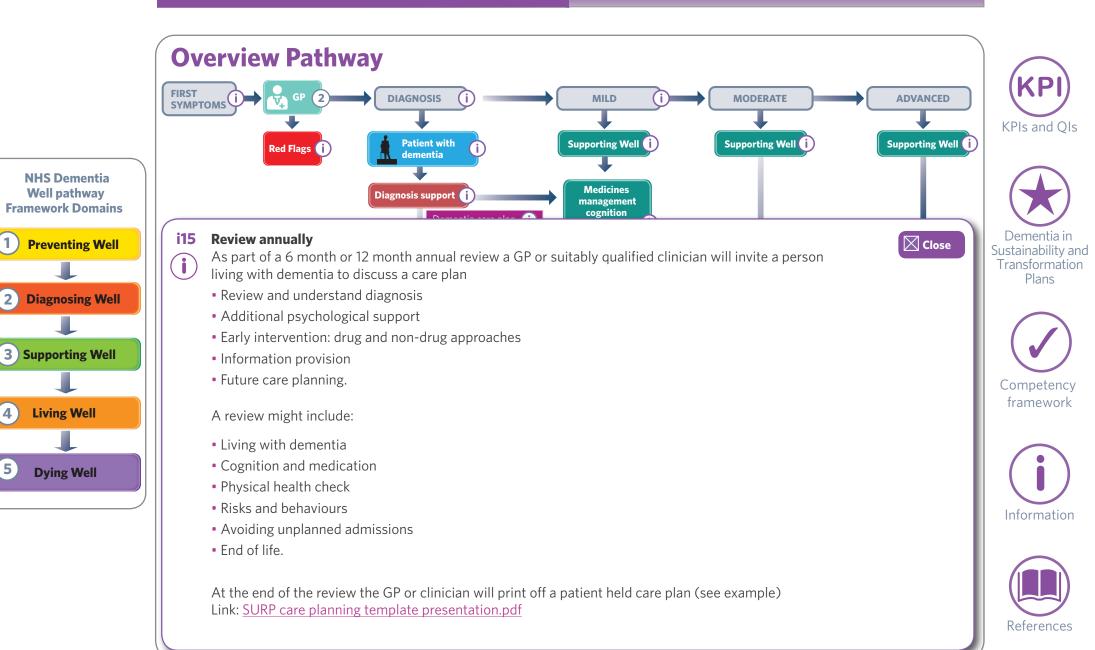
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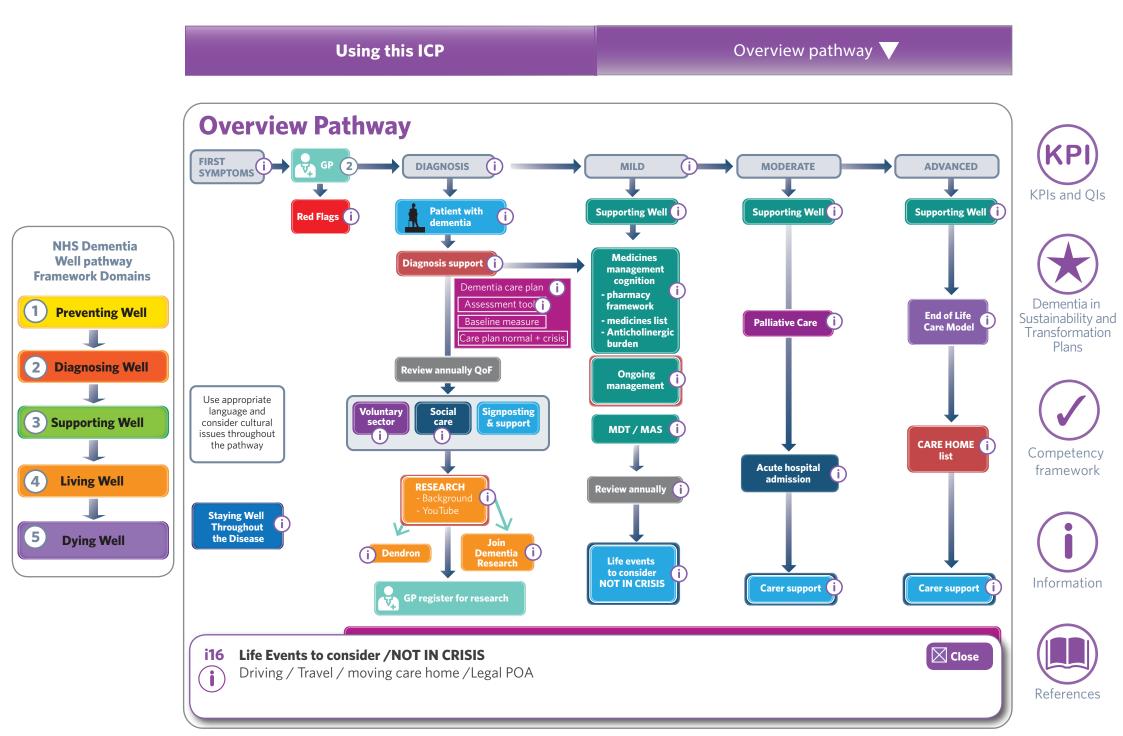
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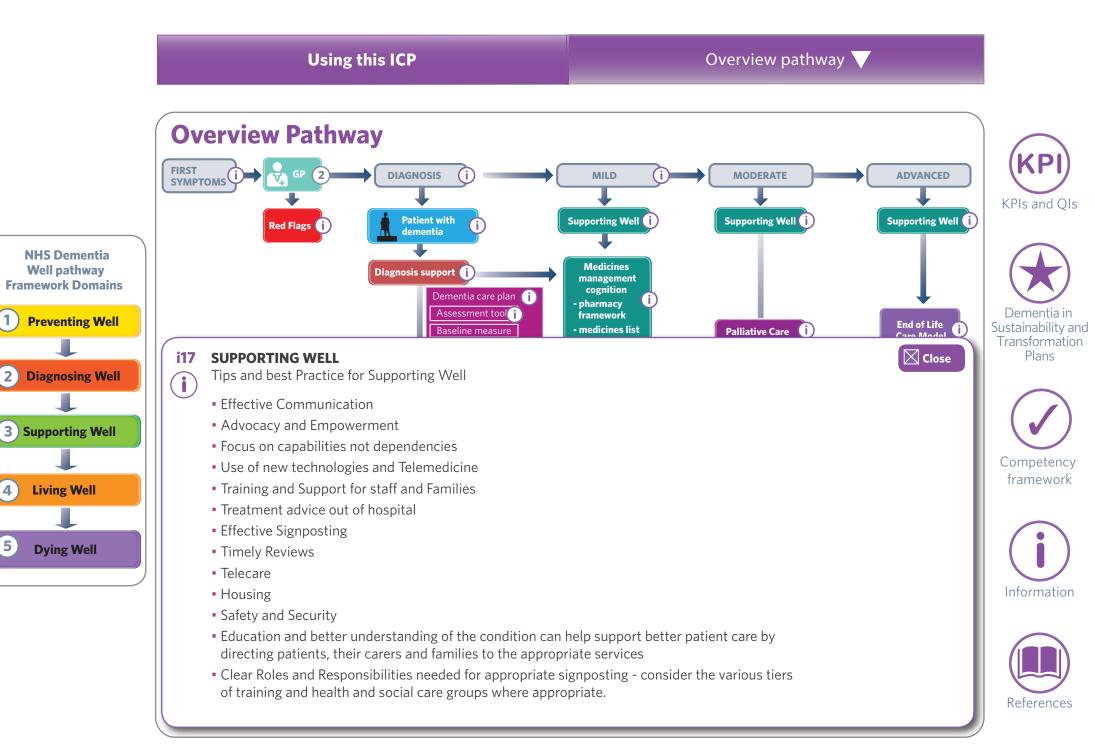
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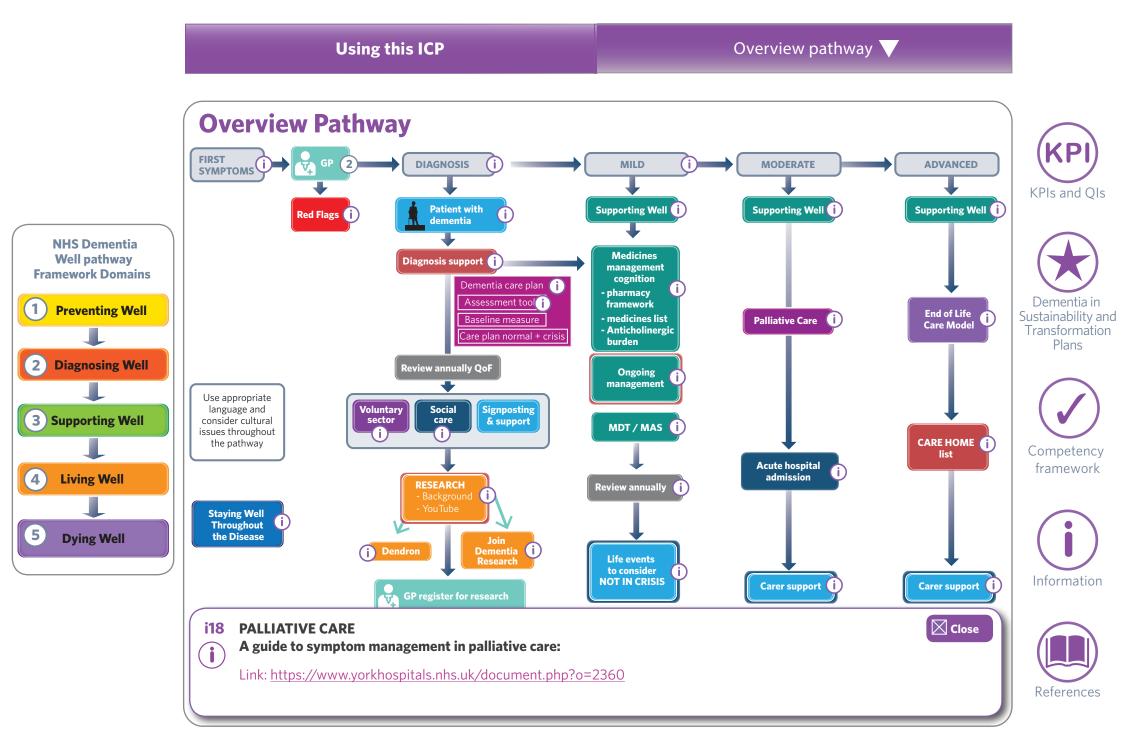
Overview pathway 🗸

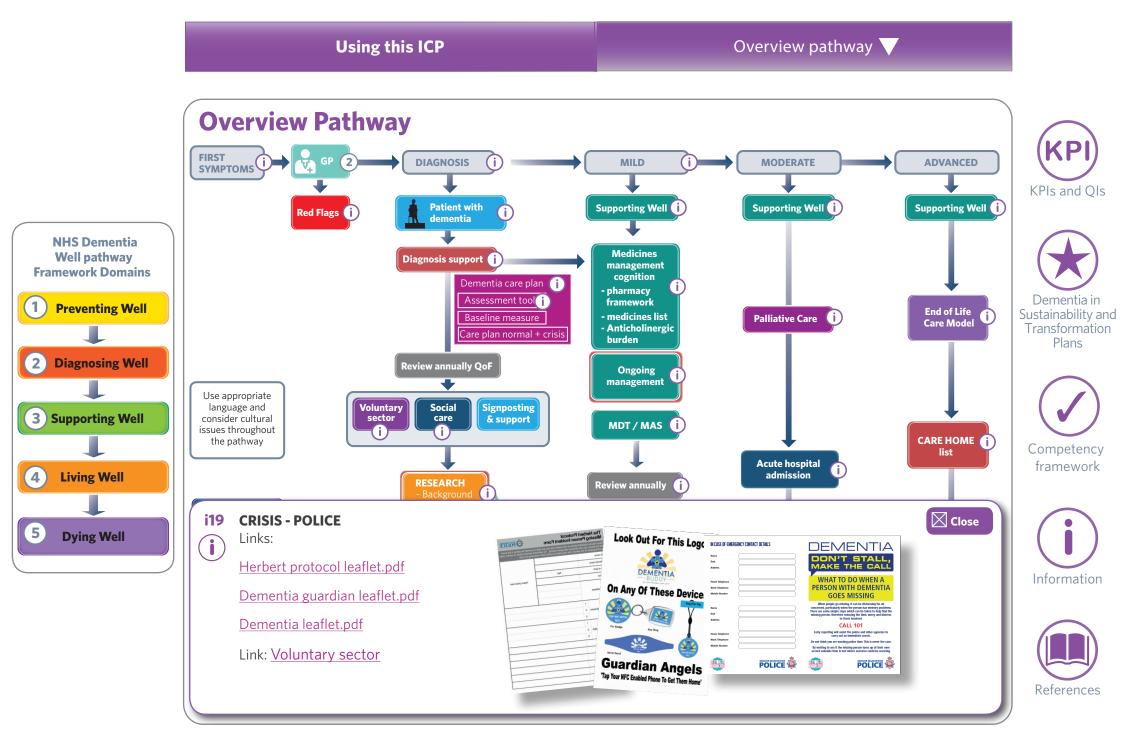


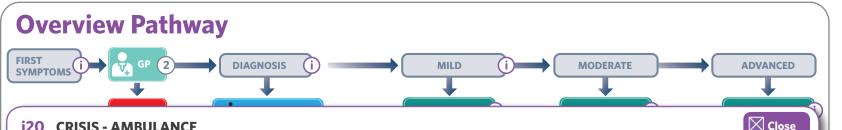




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i20 CRISIS - AMBULANCE

i Message in a bottle

NHS Dementia

Well pathway **Framework Domains**

Preventing Well

Diagnosing Well

Supporting Well

Living Well

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'Message in a Bottle' is an emergency information scheme that gives an ambulance crew (and other emergency services) basic information about a patient that may allow a person to be maintained at home rather than admitted to hospital.

Place a small plastic bottle in the fridge containing details of family, friends or local organisations who can take a caring role in an emergency and give baseline information about the person's condition. Stickers on your fridge door and on the front door can let people know it's there. This means that should the emergency services need to visit they will know exactly where to look for this important information.

Bottles, which are free of charge, can usually be found in chemists or doctors' surgeries.

Support from family and friends

Family and friends can play a vital role in an emergency. It is important that they know in advance, what responsibilities they have and provide them with important information which may include:

- Disability, illness or condition
- Medication
- Likes and dislikes
- GP contact details
- Any other people involved

Links:

https://mycare.rochdale.gov.uk/web/portal/pages/help/carers/careremergency/bottle http://lions105ea.com/specialist officer/miab.html

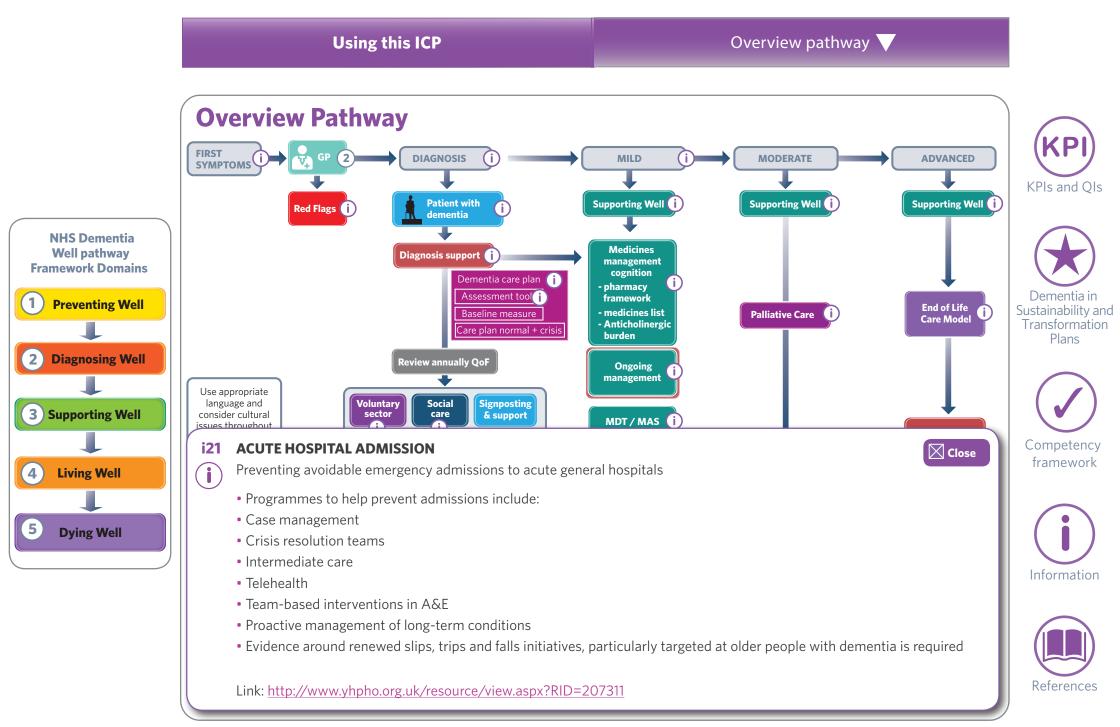


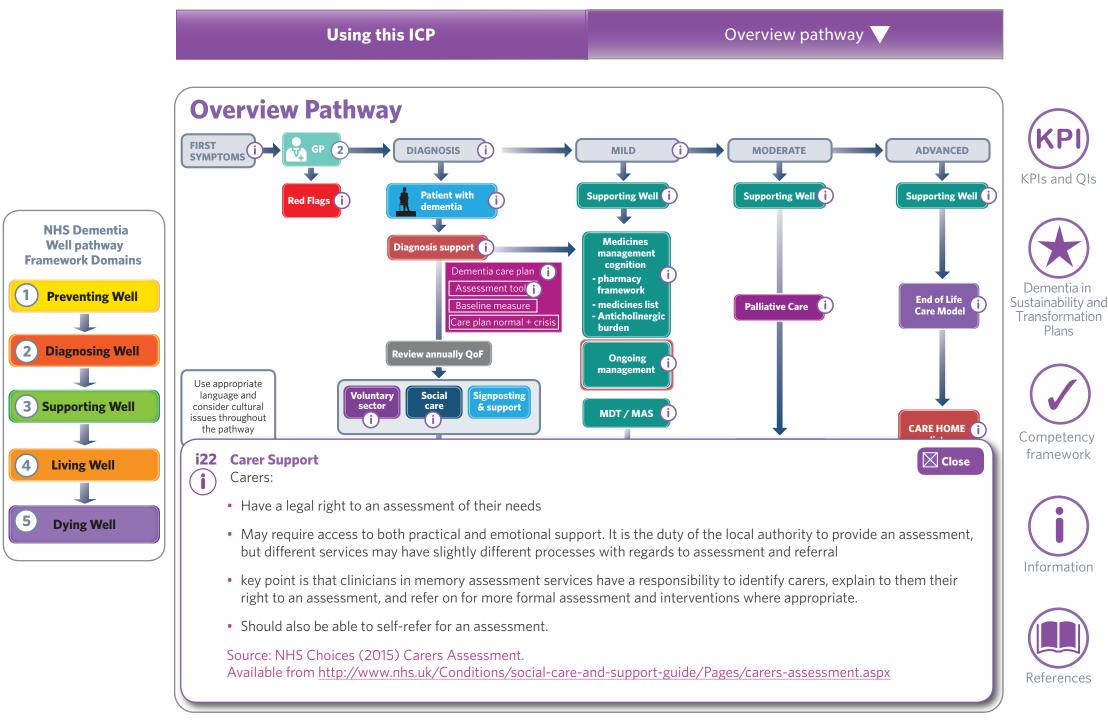


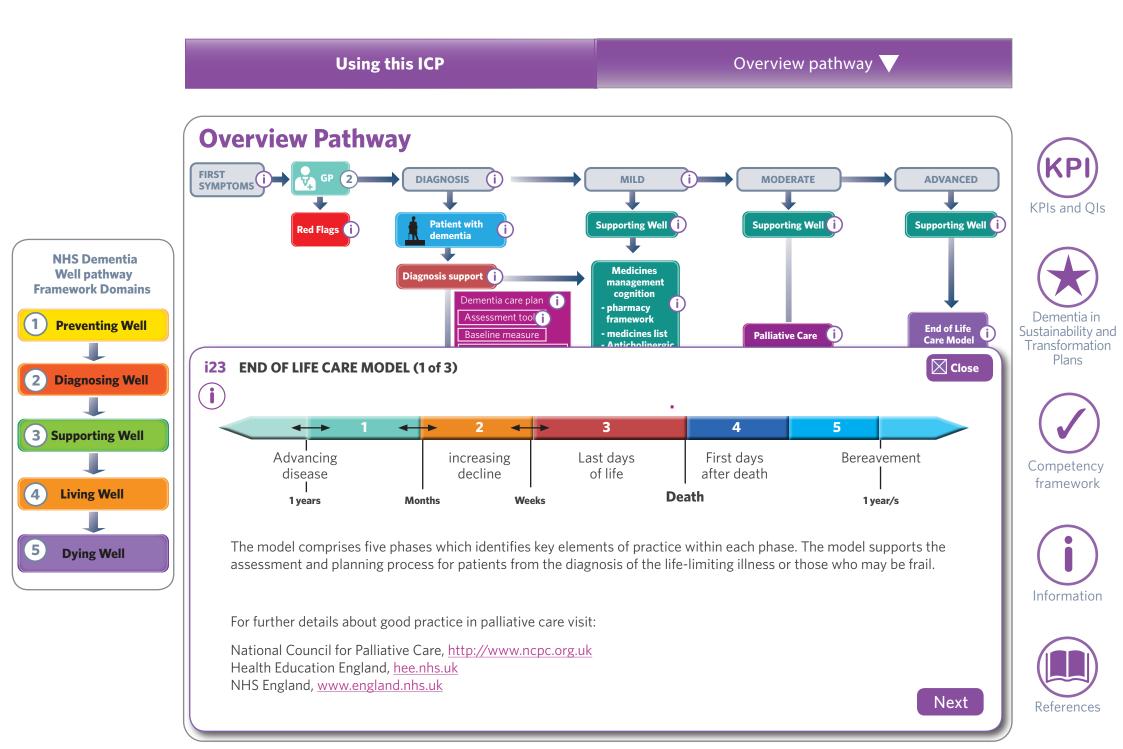












(i	Overview Pathway 123 END OF LIFE CARE MODEL (2 1)	2 of 3)		
	LAST YEAR OF LIFE Year/s	INCREASING DECLINE Months/Weeks	LAST DAYS OF LIFE Days	CARE AFTER DEATH 1 year/s
HS Dementia Vell pathway ework Domains Preventing Well Diagnosing Well Living Well Dying Well	 Patient identified as deteriorating despite effective management of underlying medical condition(s) Clear, sensitive communication with patient and those identified as important to them Person and agreed others are involved in decisions about treatment and care as they want Needs of those identified as important are explored, respected and met as far as possible Patient included on Supportive Care Record /GP Gold Standards Framework register and their care reviewed regularly Request consent to share information and create EPACCS record 	 Medical review All reversible causes of deterioration explored Clear, sensitive communication with patient and those identified as important to them Person and agreed others are involved in decisions about treatment and care as they want Needs of those identified as important are explored, respected and met as far as possible Prioritised as appropriate at Gold Standards Framework meeting On-going District Nurse support Agree on-going monitoring and support to avert crisis Holistic needs assessment 	 Medical review All reversible causes of deterioration explored Multidisciplinary Team agree patient is in the last days of life Clear, sensitive communication with patient and those identified as important to them Dying person and agreed others are involved in decisions about treatment and care as they want Agree on-going monitoring and support to avert crisis Advance Care Planning discussion offered or reviewed On-going District Nurse support ICD discussion and deactivation if not previously initiated 	 Nurse verification of death where indicated Certification of death Clear sensitive communication Relatives supported Department for Work & Pensions 011 Booklet; What to do after a death or similar Post death Significant event analysis Update Supportive Care Record/ Gold Standards Framework Register/EPaCCS with date and place of death Inform all relevant agencies; social care, Allied Health Professional, ambulance service, OOH, Specialist Palliative Care Team, equipment store











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NHS Dementia Well pathway Framework Domains	
1 Preventing Well	
2 Diagnosing Well	
3 Supporting Well	
4 Living Well	
5 Dying Well	

3 END OF LIFE CARE MODEL (3 of 3)					
LAST YEAR OF LIFE Year/s	INCREASING DECLINE Months/Weeks	LAST DAYS OF LIFE Days	CARE AFTER DEATH 1 year/s	KPIs and	
 Holistic needs assessment Keyworker identified Identify when there is an opportunity to offer an Advance Care Planning discussion and/or refer on. ADRT/PPC/MCA/ DNACPR/ making a will Benefits review of patient and carer including Grants/ prescription exemption Provide information on Blue Badge (disabled parking) scheme Agree on-going monitoring and support to avert crisis Referral to other services e.g. Specialist Palliative Care OOH/NWAS updated including Advance Care Plan/ DNACPR ICD discussion if applicable 	 Equipment assessment Anticipatory medication prescribed and available DNACPR considered, outcome documented, information shared appropriately including ambulance service Out of Hours/NWAS updated including DNACPR status and Advance Care Plan Referral to other services e.g. 	 Decisions made are regularly reviewed and revised accordingly Individual plan of care for the dying person including holistic assessment, review of hydration and nutrition, symptom control etc. is agreed, coordinated and delivered with compassion Anticipatory medication prescribed and available to prevent a crisis Needs of those identified as important are explored, respected and met as far as possible OOH/NWAS updated Update EPaCCS Record as and when necessary Review package of care if necessary Referral to other services e.g. Specialist palliative care 	 Funeral attendance if appropriate Follow up bereavement assessment to those identified as important Referral of those identified as important to bereavement counselling services as required Staff supported 	Dementia Sustainabili Transform Plans Compete framewo	

NHS Dementia

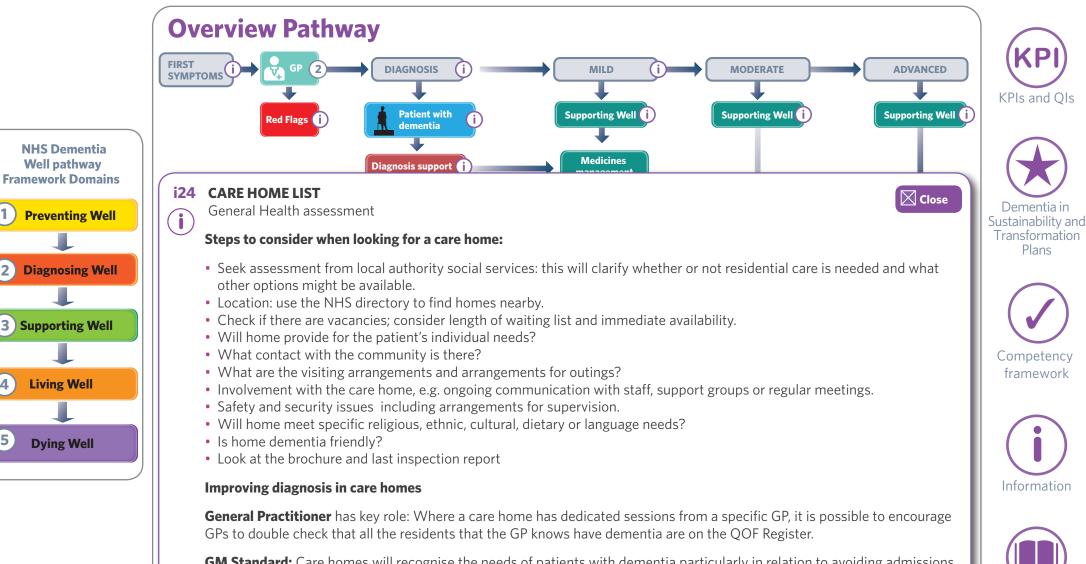
Well pathway

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Overview pathway 🗸



GM Standard: Care homes will recognise the needs of patients with dementia particularly in relation to avoiding admissions to hospital where possible. They will recognise the symptoms of dementia. They will know how to deal with the behavioural manifestations of dementia, avoiding medication where possible.

Overview Pathway

i25 AVOIDANCE (1 OF 3)

i

Cognitive and functional decline often coexist, posing a significant threat to independence. In people with dementia it is often possible to categorise this decline as acute or sub-acute, based on the time it has taken to evolve.

Acute decline: delirium

It is unusual for dementia to deteriorate suddenly, outside of rare conditions such as vCJD or the stepwise decline of vascular dementia. In the majority of cases an acute cognitive decline, hours to days or even short weeks, is likely to be due to delirium. Such change should trigger a thorough assessment, in order to identify and address acute precipitants (there will often be more than one) and predisposing factors.

In essence, in an individual at risk, almost any acute illness or change in environment may be enough to trigger delirium.

- Common predisposing factors include but are not limited to:
- 1. Polypharmacy (particularly consider anti-cholinergic drug burden)
- 2. Frailty
- 3. Dementia
- 4. Long-term urinary catheter
- 5. Chronic disease, especially neurological disease, i.e. Parkinson's disease.

Common precipitants include but are not limited to:

- 1. Infection (Caution: urinary tract infection is often over-diagnosed in this scenario)
- 2. Medication changes particularly opiate / anti-cholinergic / sedative
- 3. Pain
- 4. Constipation
- 5. Urinary retention and urinary catheterisation
- 6. Electrolyte imbalance (Na, Ca, Glucose)











Framework Domains

 1
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 2
 Diagnosing Well

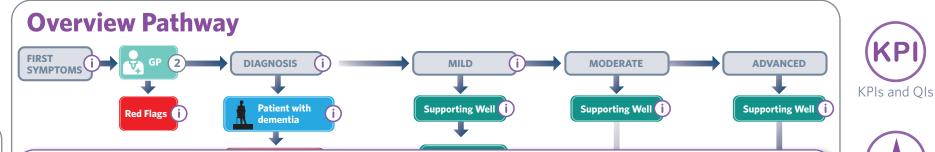
 3
 Supporting Well

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 Living Well

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 Dying Well

NHS Dementia

Well pathway





NHS Dementia Well pathway

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i Preventing delirium

Proactive identification and reduction of predisposing factors where possible. Examples include joint GP / geriatrician / pharmacist ward rounds in care homes.

Assessing delirium

Look for cardinal features. Begin assessment in the community identifying and reversing precipitants. Thorough assessment will often require involvement of secondary care services, either through intermediate care or hospital assessment (such as frailty unit), to exclude significant underlying illness.

Subsequent response

- Communication: Delirium may take weeks or even months to resolve with individuals often not regaining previous baseline function, this should be discussed so that expectations are realistic.
- Care planning: Permanent decisions regarding place and intensity of care should be delayed until extent of recovery (cognitive and functional) is clear.
- Prevention: Address underlying risk factors where possible to reduce risk of recurrence.

Gradual decline

Gradual decline may be due to deterioration in underlying dementia, often punctuated by periods of delirium as described above.

Acute hospital admission should be avoided if at all possible – unlikely to be helpful and may precipitate delirium / lead to hospital-acquired harm.

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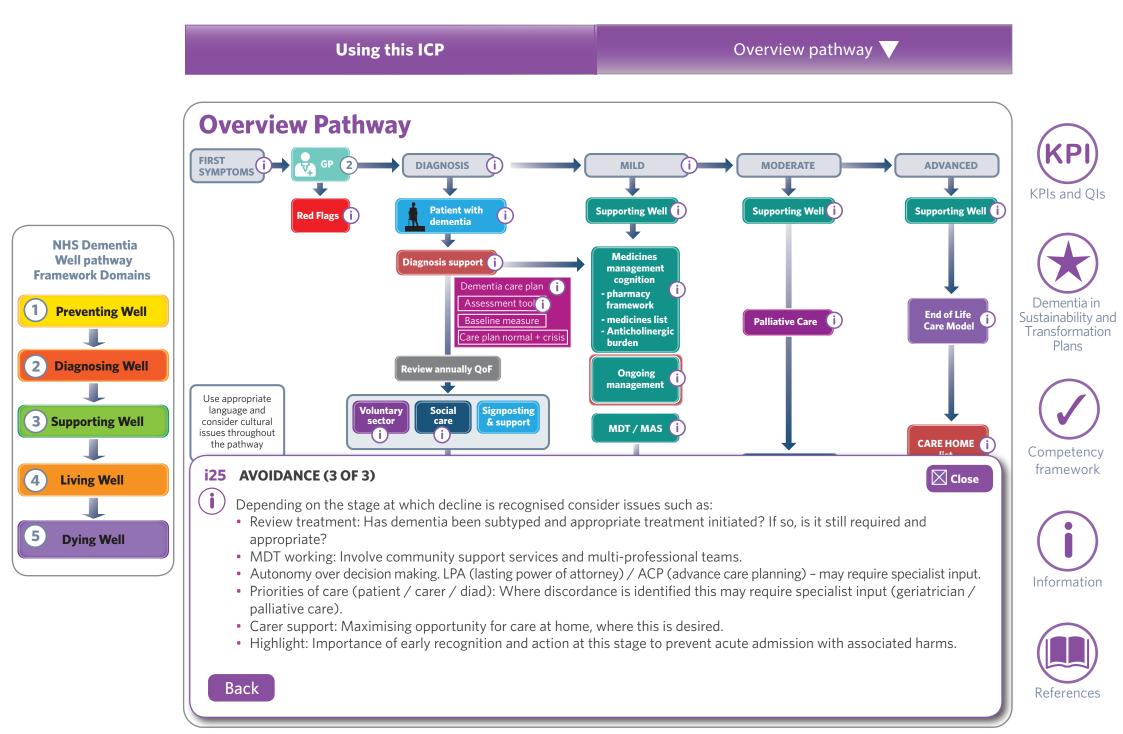
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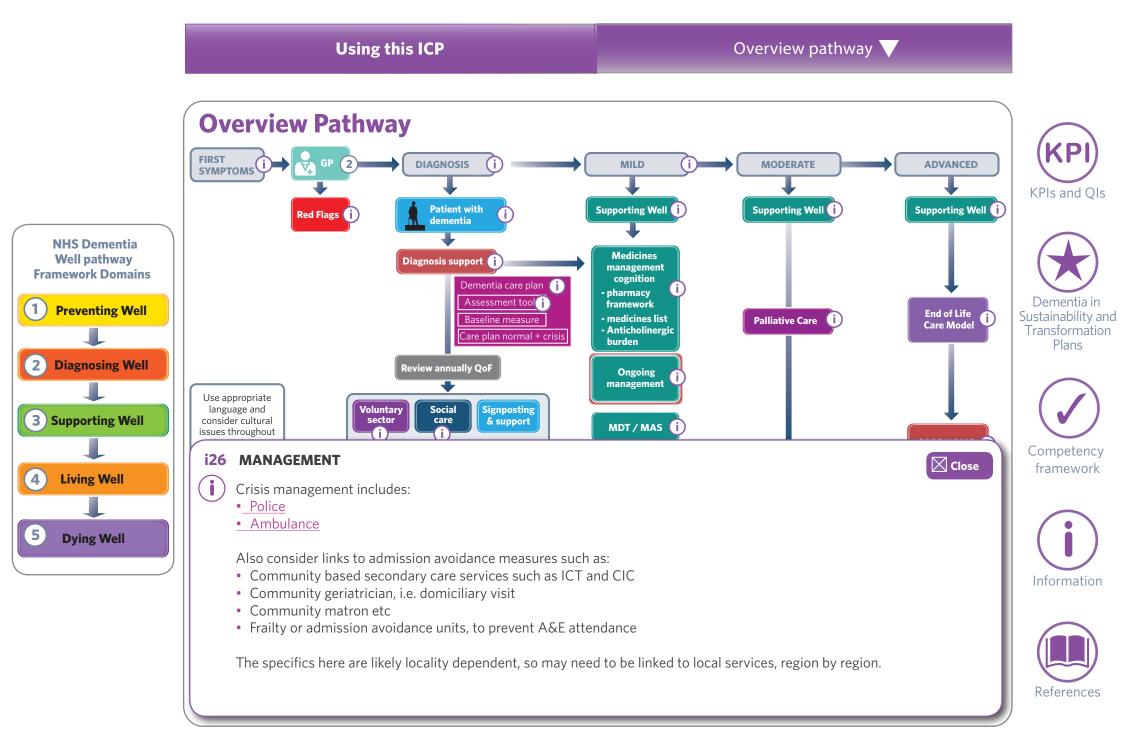
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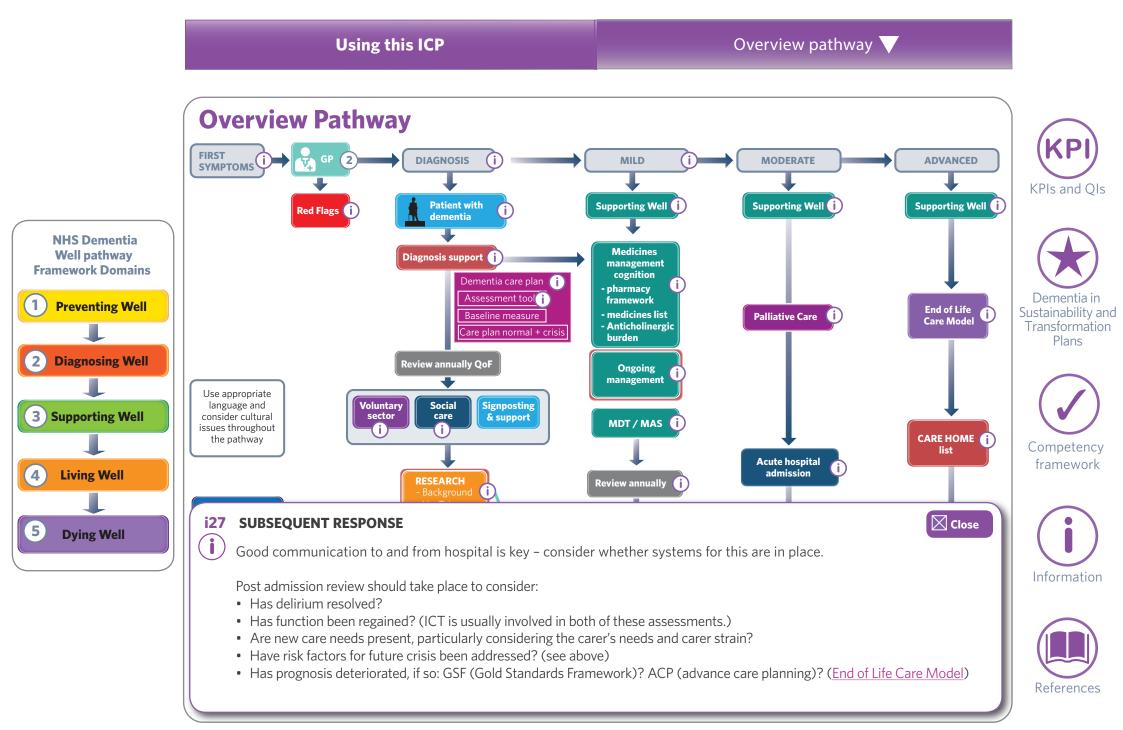


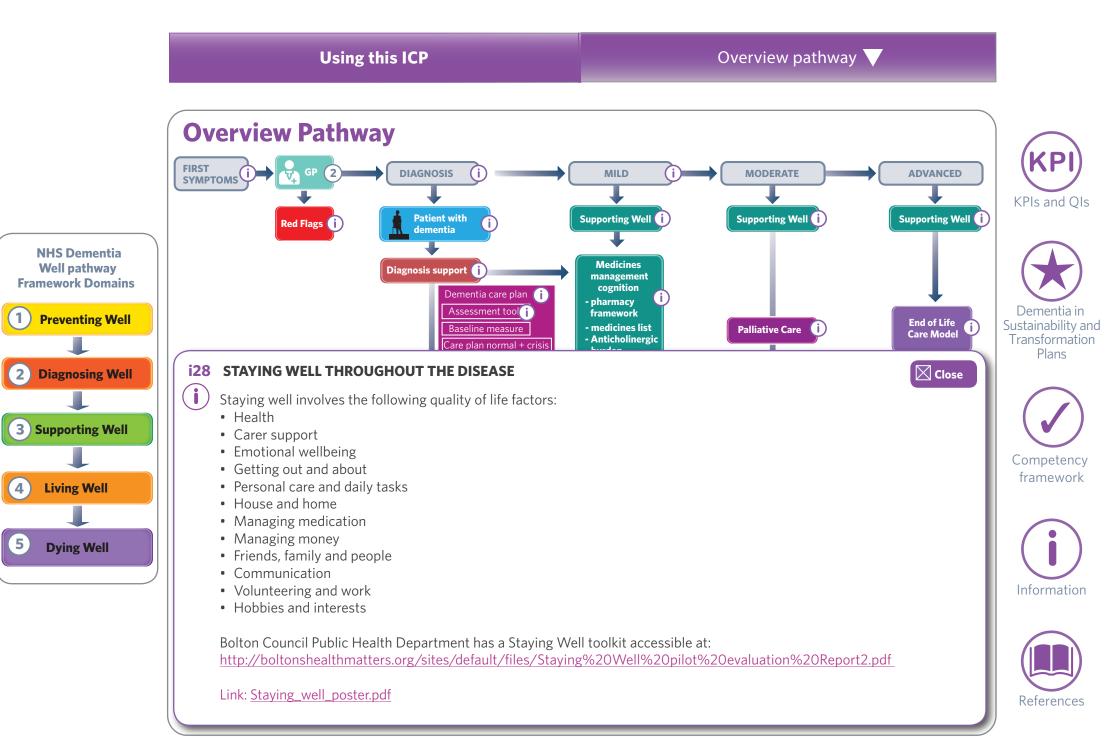






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KPI KPIs and QIs

The key performance indicators for dementia are described in '**The Government's mandate to NHS England for 2016-17'** (Section 4.2)

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/494485/NHSE_mandate_16-17_22_Jan.pdf

Overall 2020 goals:

- Measurable improvement on all areas of Prime Minister's challenge on dementia 2020, including:
- maintain a diagnosis rate of at least two thirds;
- increase the numbers of people receiving a dementia diagnosis within six weeks of a GP referral; and
- improve quality of post-diagnosis treatment and support for peoplewith dementia and their carers.

2016-17 deliverables:

- Maintain a minimum of two thirds diagnosis rates for people with dementia.
- Work with National Institute for Health Research on location of Dementia Institute.
- Agree an affordable implementation plan for the Prime Minister's challenge on dementia 2020, including to improve the quality of postdiagnosis treatment and support.









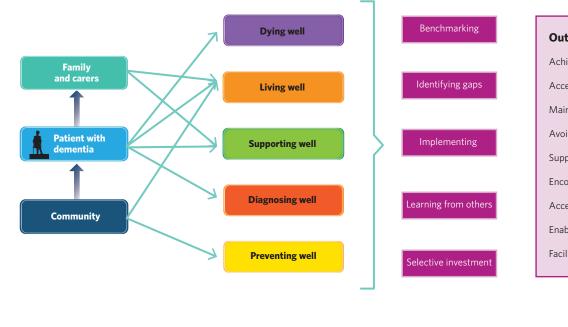


Dementia in Sustainability and Transformation Plans (1 of 5)

Dementia is a key aspect of STPs, within mental health, and is one of the "must do's" with specific mentions of maintaining the national diagnosis rate at two thirds, tackling variation between CCGs and improving the provision of post diagnostic treatment and support.

The text in this section, supplied by the National Clinical Director for dementia may be of some assistance, suitably amended for local circumstances.

Sustainability and Transformation Plan for Dementia







Next









Dementia in Sustainability and Transformation Plans (2 of 5)

Dear colleagues

A personal clinical view on how dementia may figure in Sustainability and Transformation Plans

Dementia is a key aspects of STPs, within mental health, and is one of the "must do's" with specific mentions of maintaining the national diagnosis rate at two thirds, tackling variation between CCGs and improving the provision of post diagnostic treatment and support.

Some people have asked if I could provide some advice about what should be in the plans around dementia. The attached text may be of some assistance, suitably amended for local circumstances. Some additional examples are given in the annex. There is also a slide which attempts to summarise the situation.

"We propose a bold **transformation** of the way in which the needs of people with dementia and their carers are addressed by the health and social services with an emphasis on **prevention** (both primary prevention and avoiding additional disability due to co morbid conditions), **maintaining independence** for people with dementia in their communities (specifically avoiding unnecessary hospital admissions) and providing **high quality support** for families and carers. The overall aim is for the efficiencies to lead to **sustainable** high quality care.

We will achieve this by:

Benchmarking our services and identifying our strengths in dementia care using local and national information such as that available through the PHE Fingertips tool, the CCG Improvement and Assessment Framework and NHS Digital.

Identifying where gaps exist

Learning from models of good practice from within our STP footprint and nationally

Implementing and monitoring the impact of NICE guidelines and Quality Standards and the Achieving Better Access standards

Using selective investment and developing an economic model to facilitate sustainability of our plans"

I hope this is of some interest

Alistair Burns Alistair.burns@nhs.net June 2016

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Dementia in Sustainability and Transformation Plans (3 of 5)

Annex

Some examples from the Wellbeing Pathway (including the relevant "i" statement)

Preventing Well

"I was given information about reducing my personal risk of dementia"

There is good evidence that a proportion (estimates vary but 10-15% has been cited) of diagnoses of dementia could be avoided by rigorous management of vascular risk factors – what's good for your heart is good for your head. Prevention is led by PHE and information about risk reduction is included in current Health Checks. Prevention messages have the advantage of portraying a positive mood and our relevant to a generation younger than those generally thought to be affected by dementia.

By 2020, every person will be aware of their personal risk of dementia which can be part of the NHS Health Check, identifying people at higher risk of developing dementia and relatives of people with dementia.

Diagnosing Well

Back

"I was diagnosed in a timely way and told about research"

A raft of initiatives have been implemented by NHS England and taken up by CCGs with a demonstrable improvement in diagnosis rate over the last year. Monthly contact with CCG's and mobilisation of regional teams has been successful as well as getting support for the clinical message of the benefits of a diagnosis. New treatments for the commonest cause of dementia, Alzheimer's disease, have a realistic prospect of success which will change the landscape of assessment and treatment. We will work with partners in NICE, NHS Improvement and NHS England in the provision of clinical advice and commissioning guidance.

By 2020, the overall diagnosis rate maintained at two thirds of the estimated number of people with dementia, every person who wishes a diagnosis will have that, where clinically appropriate, within six weeks of referral and 25% of people with dementia will have been given the opportunity to take part in research.

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Dementia in Sustainability and Transformation Plans (4 of 5)

Supporting Well

"Those around me and looking after me are supported"

The cornerstone of this is post diagnostic support – the time immediately following a diagnosis where there is a need for advice and often practical help. Increasingly the discussion is around peri-diagnostic support and in many areas this is already offered. People with dementia and their carers say that support ideally needs to be from a single person, the advice needs to be bespoke and response needs to be timely. Dementia advisors are a key part of this and a three step approach of support (ABC) with Advice and information provided in general, Bespoke information available when needed with Complex clinical care provided by Admiral nurses (dubbed McMillan nurses for dementia).

By 2020, everyone person with a diagnosis of dementia will have a personalised care plan and their families and carers will be able to say that the support they received met their needs. In addition, all health and social care professionals should have a basic understanding of dementia in line with the core competencies published by Health Education England, with information reported by CQC and NHS England.

Living Well

"I feel included and I am treated with dignity and respect"

This is a responsibility that goes way beyond health, there is an aspiration of four million dementia friends by 2020 to add to the one million already there, there are many examples around the country of dementia friendly cities, dementia friendly communities, dementia friendly schools, dementia friendly businesses which are enormously innovative it is that lived experience of dementia which is the hallmark here. Health Education England have recently published their core competencies

By 2020, every person with dementia should be able to say that their communities and organisations with whom they have contact treated them with dignity and respect, every hospital will have signed up to John's Campaign.



Next









Dementia in Sustainability and Transformation Plans (5 of 5)

Dying Well

"I am confident my end of life wishes will be respected"

Much has been written about and opined regarding end of life care in dementia. One of the challenges is that dementia is not always considered a terminal illness (although the life expectancy of someone with dementia in a care home is the same as a women with metastatic breast cancer) and there is widespread everyone seems to be worried about issues of capacity.

By 2020, every person dying with dementia will have an Advanced Care Plan has been managed according to the NICE End of Life Care Guidelines.



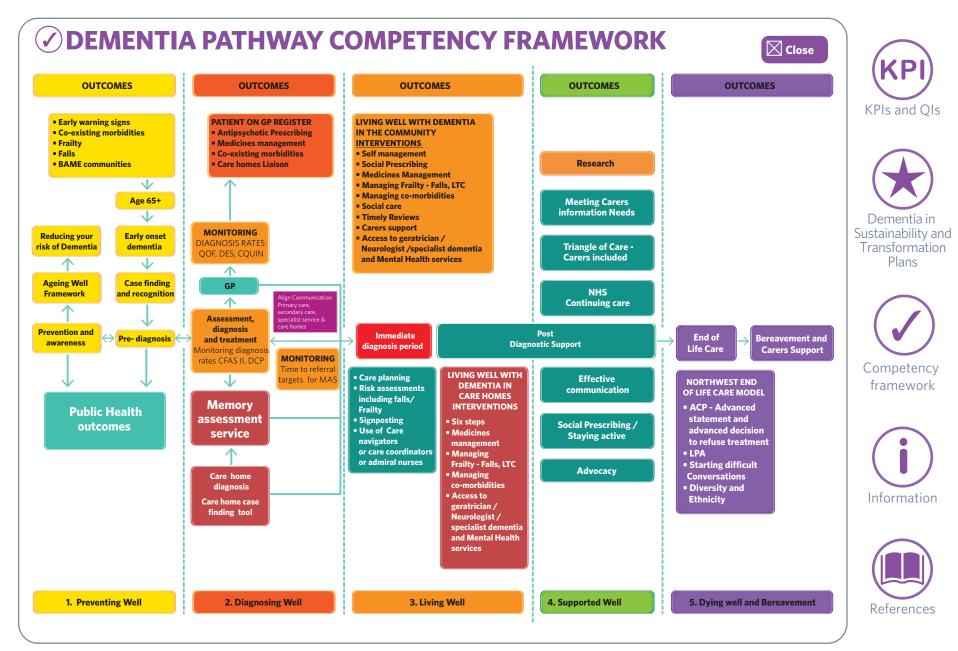


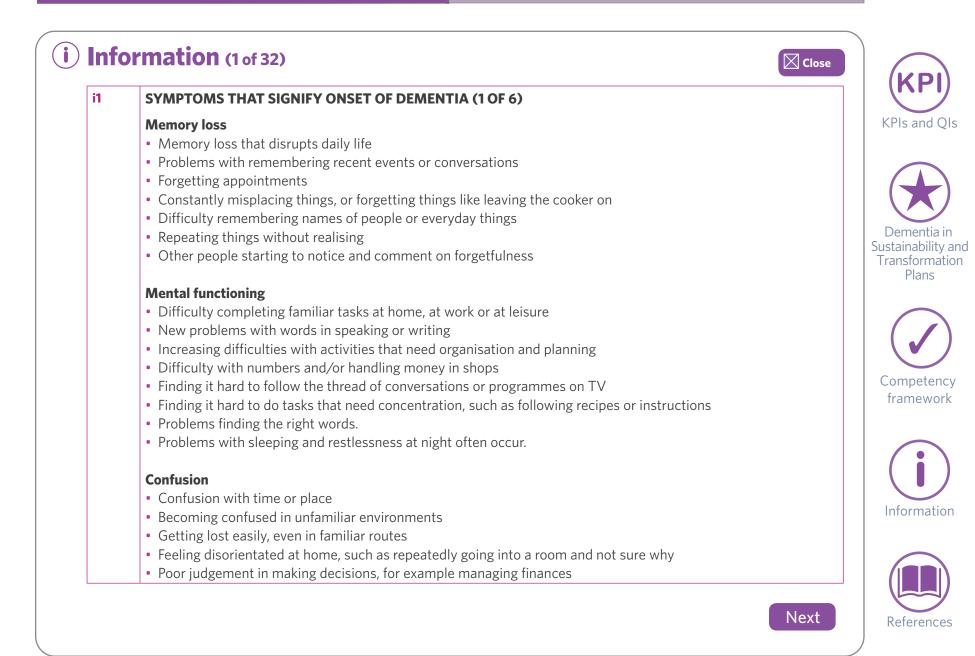


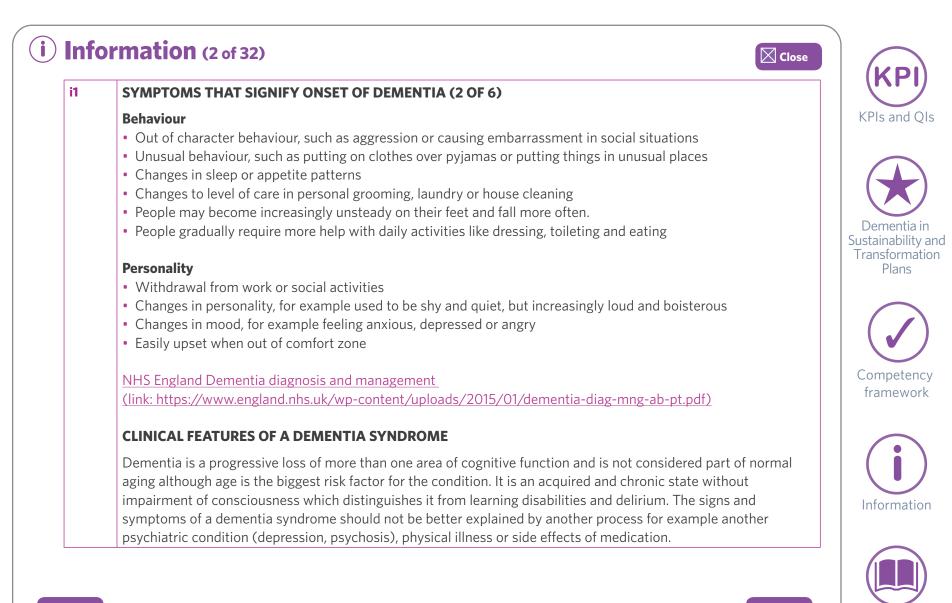




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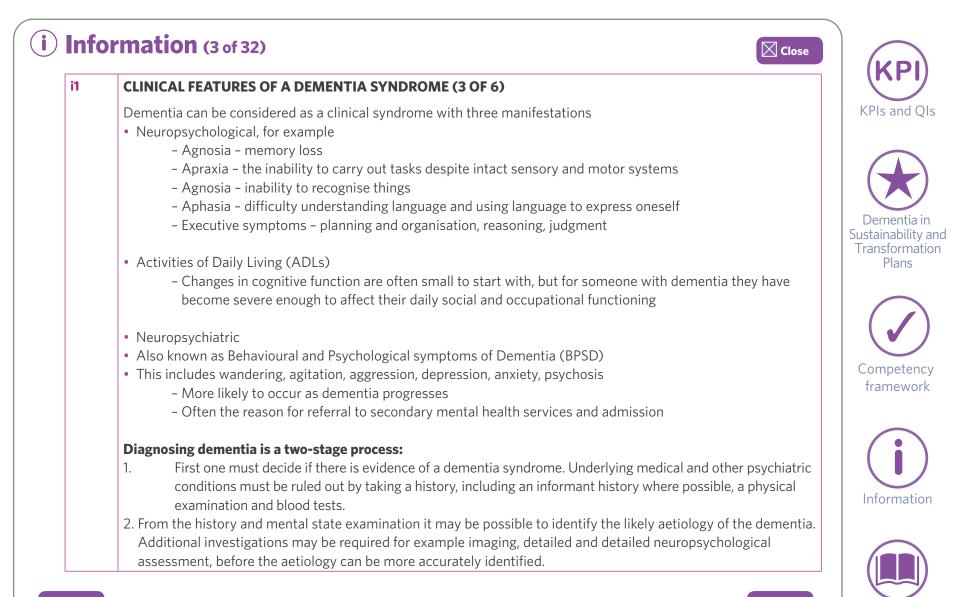






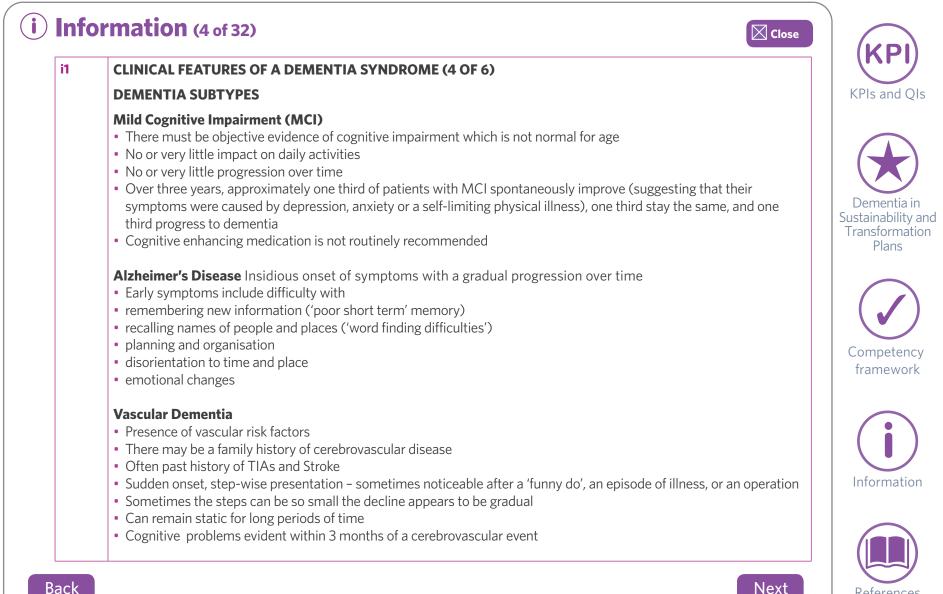
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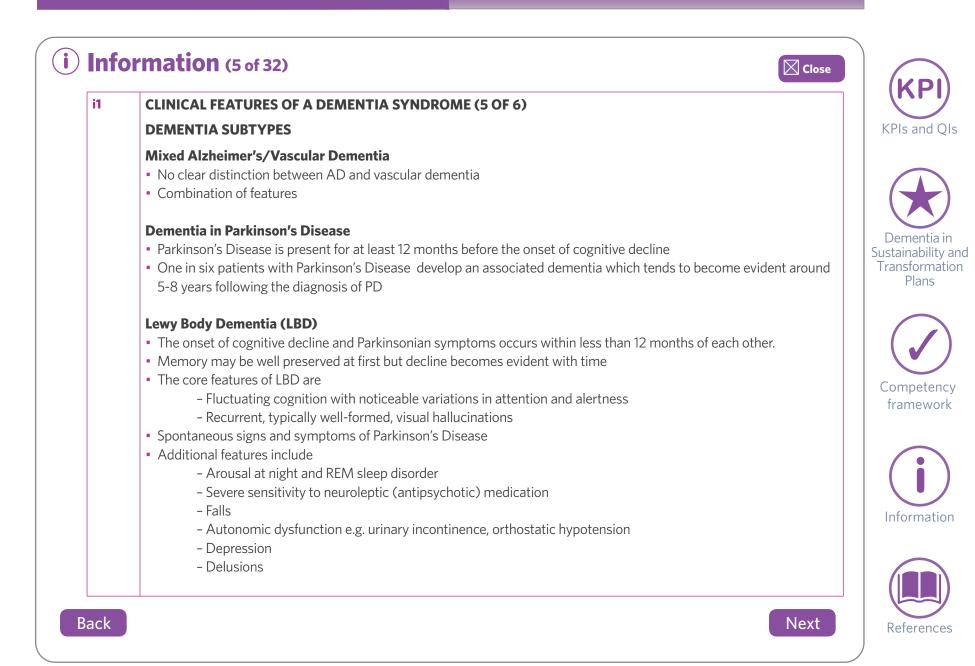
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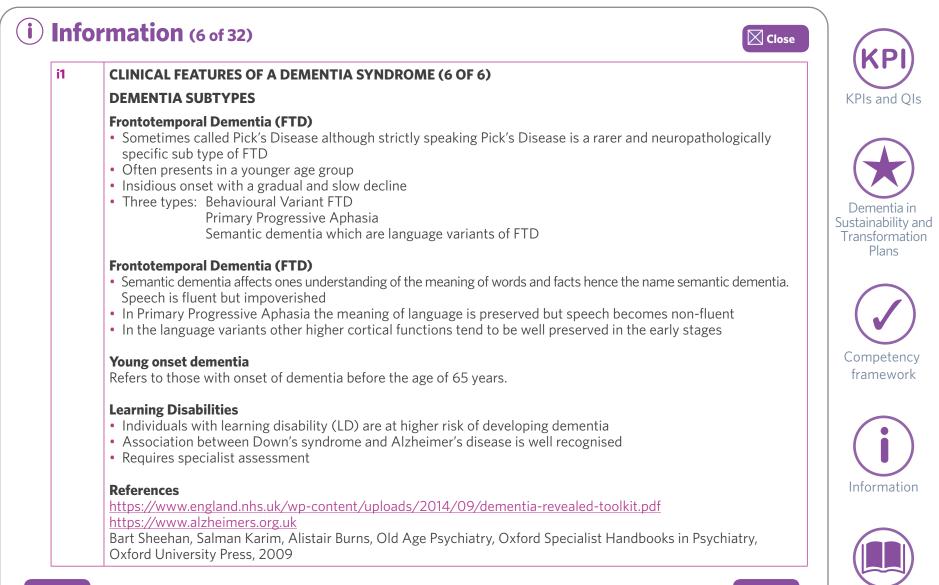












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i2	DIAGNOSIS Assessment tools for diagnosis and monitoring in dementia https://www.england.nhs.uk/wp-content/uploads/2014/09/dementia-revealed-toolkit.pdf							
i3		RED FLAGS FOR GPS SUSPECTING DEMENTIA First symptoms and red flags that indicate dementia include:						
	Dementia with Lewy bodies	Normal pressure hydrocephalus	Cortical-basal degeneration					
	Early depression	Multiple falls	Early apraxia	Dem Sustain				
	Visual hallucinations Gait change Unilateral symptoms							
	Facial expression	Incontinence	Alien limb	P				
	Autonomic dysfunction							
i4	PATIENT WITH DEMENTIA Baseline "Normal assessment / Care plan - Normal patient details / Crisis support / Fears patient may have							
i5	SUPPORT AT DIAGNOSIS							
	To support Immediate and ongoing post diagnostic Support, see useful guidance and best practice:							
	NICE guideline CG42 includes recommendations on:							
	Integrating health and social care Disk forthere prevention and care							
	Risk factors, prevention and early identification							
	Diagnosis and assessment Interventions for cognitive and non-cognitive symptoms, and comorbid emotional disorders							
	0	Interventions for cognitive and non-cognitive symptoms, and comorbid emotional disorders						
	0	-cognitive symptoms, and comorb	a emotional disorders					





i5	SUPPORT AT DIAGNOSIS	
	Consider:	KDL
	 Holistic and person centred care (Whole system approach) 	KPIs
	Mental Health, memory loss, oral health, diet and nutrition, physical health, physical activities, cognitive	
	impairments, social inclusion and wellbeing, housing and financial support etc.	
	Supporting people with dementia: Life after diagnosis	
	 Immediate post diagnosis support guidance Guidance for Post-Diagnostic Support Planning 	
	 Guidance for Post-Diagnostic support Planning Commissioner checklist for dementia 	
	What to expect from good quality dementia services	Dem Sustain
i6	DEMENTIA CARE PLAN - Sample care plan	Transf
10	Link: SURP care planning template presentation.pdf	P
	Care planning	
	As part of a 6 month or 12 month annual review a GP or suitably qualified clinician will invite a person living	
	with dementia to discuss a care plan :	
	Review and understand diagnosis	
	Additional psychological support	
	Early intervention: drug and non-drug approaches	Comp
	Information provision	fram
	Future care planning	
	A review might include:	
	Living with dementia	
	Cognition and medication	
	Physical health check	
	Risks and behaviours	Infor
	Avoiding unplanned admissions	
	• End of life	
	At the end of the review the GP or clinician will print a patient-held care plan.	





i6	DEMENTIA CARE PLAN - Sample care plan	
	Link: SURP care planning template presentation.pdf	KPIs and QIs
	Improving uptake of care plans	
	 All professionals providing care for patients need to be clear and agree responsibility for having care plan discussions across teams and organisations 	
	 Education and training of healthcare professionals needs to be implemented about the importance of, and approach to, care plans (advance care planning and end-of-life care) 	
	 Awareness needs to be raised among the general public, patient support organisations and the voluntary sector about the benefits and how to confidently initiate advance care planning discussions themselves 	Dementia in Sustainability and Transformation Plans
7	ASSESSMENT TOOLS FOR DIAGNOSIS AND MONITORING IN DEMENTIA Neurophysiological testing is extremely useful and important in helping to both diagnose and monitor patients with cognitive impairment and dementia. Along with the history, examination and imaging findings, it is an integral component of the diagnostic process.	
	Mild cognitive impairment (MCI) is evident on formal cognitive testing, however does not present with any clinically significant impairment on daily functioning. Therefore cognitive testing is the most common and meaningful way to diagnose MCI. For some time now many clinicians have used the Mini Mental State Examination to assess cognition. However this diagnostic tool is many decades old and does not correlate well with current ICD-10 diagnostic criteria. It focuses mainly on amnesia but fails to assess other key areas of cognitive impairment and dementia such as aphasia, apraxia and agnosia. As such the MMSE is not sensitive to early changes in these domains. Furthermore, other cognitive assessments adjust for educational ability which the MMSE does not. Below are three cognitive assessment tools which have been shown to be sensitive, accurate and achievable in a primary care setting.	Competency framework

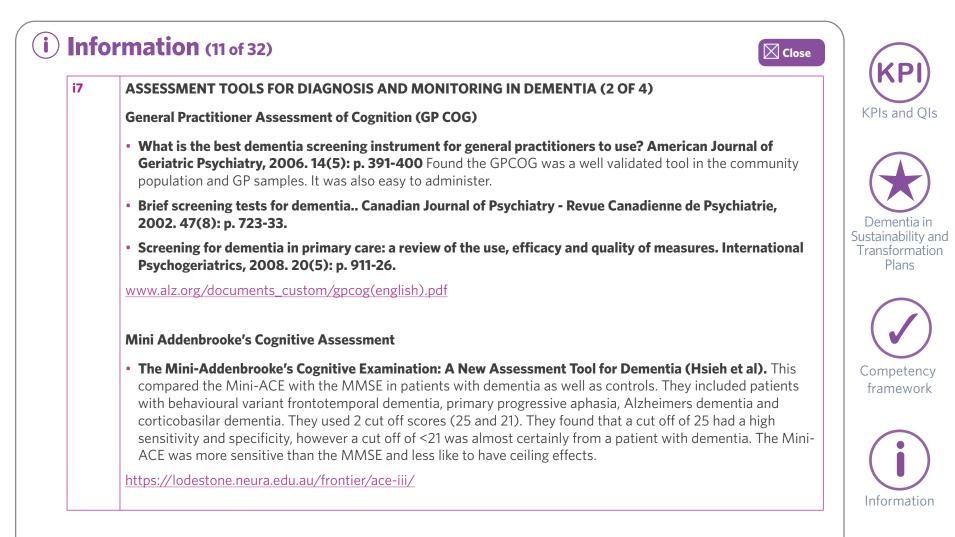


ASSESSMENT TOOLS FOR DIAGN	OSIS AND MONITORING IN DEMENTIA	A (1 OF 4)
Montreal Cognitive Assessment	General Practitioner Assessment	Mini Addenbrooke's Cognitive
(MoCA)	of Cognition (GP COG)	Assessment (Mini ACE)
One page 30 point test	A brief screening test for cognitive	A brief cognitive screening tool for
Administered in 10 minutes	impairment, taking less than 10	dementia.
Tests several areas of memory	minutes, specifically designed for	It is a 30 point test and contains
including:	primary care. It consists of:	items assessing:
 Recall memory Visuospatial abilities Executive functioning Attention and concentration Language Orientation A number of studies have assessed the validity of the MoCA in a variety of different patient groups and have demonstrated it to be an accurate and sensitive assessment tool for diagnosis cognitive impairment and dementia 	 Cognitive test of the patient (9 items - e.g. time orientation, clock drawing) Informant interview (6 historical questions - e.g. comparing current function to a few years ago) This assessment tool has the added benefit of an informer interview to increase the predictive power. Literature reviews recommend using this as a brief screening tool in primary care. 	

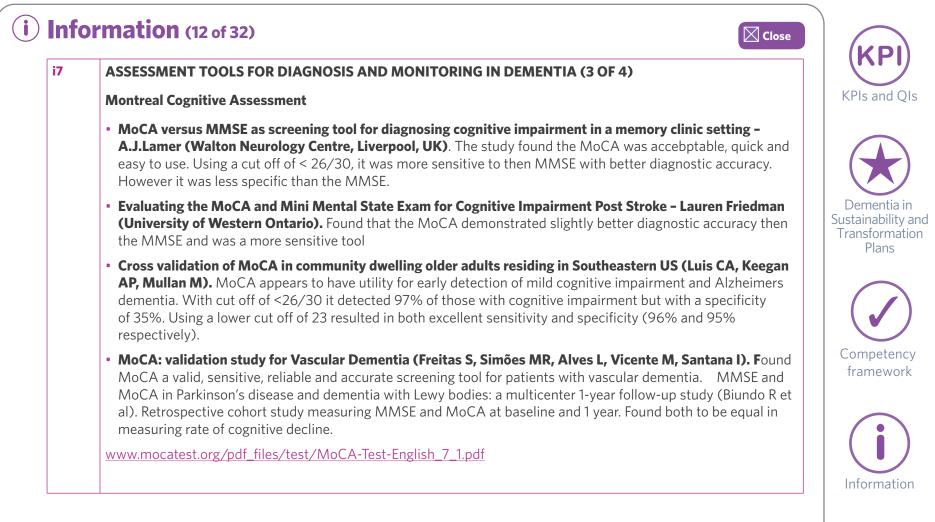




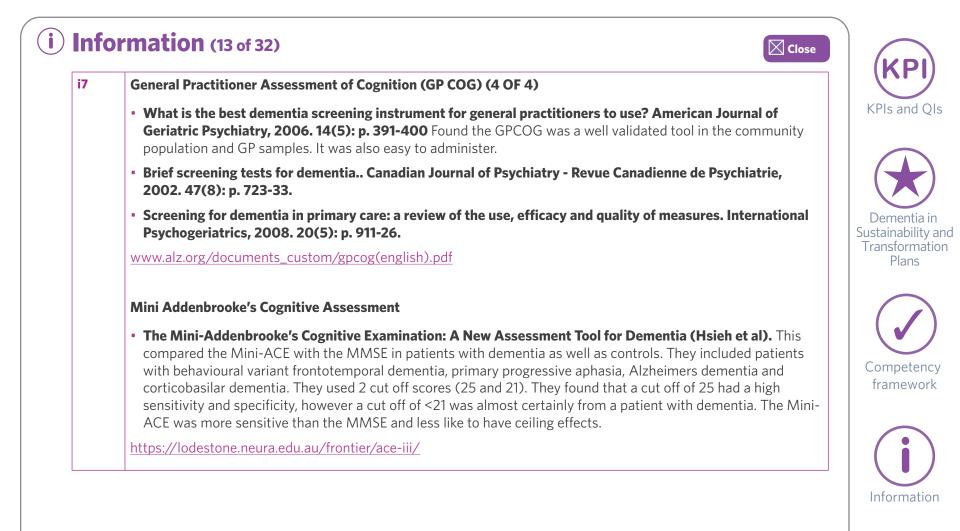
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Using this ICP

i8	VOLUNTARY SECTOR	
	Link: <u>https://www.alzheimers.org.uk/</u>	KPIs and QIs
i9	SOCIAL CARE	
	Link: http://www.scie.org.uk/search?sq=dementia+care	
	SCIE Guide 4 - Commissioning care homes: common safeguarding challenges. (SCIE, 2014)	
	SCIE Guide 15: Dignity in Care (SCIE, 2011)	Dementia in
	SCIE Guide 47 - Personalisation: a rough guide (SCIE, 2012)	Sustainability ar Transformatio
	SCIE Guide 52 - GP services for older people: a guide for care home managers (SCIE, 2013)	Plans
i10	RESEARCH	
	Link: Link: Dementia Research guidance GMLSC SCNs.pdf	
	Link: https://www.youtube.com/watch?v=BRbpXJ5WCLI	
	Link: https://www.joindementiaresearch.nihr.ac.uk/	Competency
i11	RESEARCH	framework
	Dendron	
	Link: https://www.crn.nihr.ac.uk/dementia/about-dementia-research/research/	
	Join Dementia Research	
	Link: https://www.joindementiaresearch.nihr.ac.uk/	Information



Next

When to start Carer's view on patient's condition at baseline to be sought. How to start Carer's view on patient's condition at baseline to be sought.		Acetylcholineste	erase inhibitors (Achi)		NMDA antagonist	KPIs ar
communication between nerve cells. glutamate which can damage cells. Benefits Medications do NOT slow the progression of Alzheimer's disease. They provide treatment of symptoms, and improvement is seen in 40-70% of people. Evidence in reducing delusions, agitation and aggression When to start For treatment of cognitive, global, functional or behaviour symptoms in patients with mild to moderate Alzheimer's disease For treatment of symptoms in people with severe Alzheimer's disease How to start Carer's view on patient's condition at baseline to be sought. To be initiated by specialists in care of patients with dementia. To be gradually increased over months as detailed below. OR Moderate Alzheimer's disease who are intolerant or have contraindication to Achi. When to stort Evidence of poor compliance with no available strategies to improve compliance. Careful consideration of benefits and risks. Treatment should stopped when it is considered that it is no longer having a worthwhile effect on cognitive, global,	Medication	Donepezil	Rivastigmine	Galantamine	Memantine	
They provide treatment of symptoms, and improvement is seen in 40-70% of people. aggression This may include reduction in levels of anxiety, improvement in motivation, memory, concentration and improved ability to continue activities of daily living. aggression When to start For treatment of cognitive, global, functional or behaviour symptoms in patients with mild to moderate Alzheimer's disease For treatment of symptoms in people with severe Alzheimer's disease How to start Carer's view on patient's condition at baseline to be sought. To be initiated by specialists in care of patients with dementia. To be gradually increased over months as detailed below. OR Moderate Alzheimer's disease When to stop Evidence of poor compliance with no available strategies to improve compliance. Careful consideration of benefits and risks. Treatment should stopped when it is considered that it is no longer having a worthwhile effect on cognitive, global,	Mode of Action			which improve		
symptoms in patients with mild to moderate Alzheimer's disease severe Alzheimer's disease OR Moderate Alzheimer's disease who are intolerant or have contraindication to Achi. How to start Carer's view on patient's condition at baseline to be sought. To be initiated by specialists in care of patients with dementia. To be gradually increased over months as detailed below. When to stop Evidence of poor compliance with no available strategies to improve compliance. Careful consideration of benefits and risks. Treatment should stopped when it is considered that it is no longer having a worthwhile effect on cognitive, global,	Benefits	They provide trea 40-70% of peopl This may include in motivation, me	atment of symptoms, an e. reduction in levels of ar emory, concentration an	d improvement is seen in nxiety, improvement		Demer Sustainab Transfor Pla
To be initiated by specialists in care of patients with dementia. To be gradually increased over months as detailed below. When to stop Evidence of poor compliance with no available strategies to improve compliance. Careful consideration of benefits and risks. Treatment should stopped when it is considered that it is no longer having a worthwhile effect on cognitive, global,	When to start				severe Alzheimer's disease OR Moderate Alzheimer's disease who are	
Careful consideration of benefits and risks. Treatment should stopped when it is considered that it is no longer having a worthwhile effect on cognitive, global,	How to start	To be initiated by	specialists in care of pa	itients with dementia.		Compe
	When to stop	Careful considera Treatment should	ation of benefits and risk stopped when it is con	ks. sidered that it is no longer	having a worthwhile effect on cognitive, global,	
How to stopTo taper and stop gradually over 4 week. Patient should be observed for any changes in cognition, function or behaviour.	How to stop		gradually over 4 week.	Patient should be observe	ed for any changes in cognition, function or	Inform

2	MILD - MEDICII	NES MANAGEME	NT TABLE (2 OF 3)			
		Acetylcholinesterase inhibitors (Achi)			NMDA antagonist	KPIs and
	Medication	Donepezil	Rivastigmine	Galantamine	Memantine	
	Form	Tablets Orodispersible tablets	Capsules, Oral solution Transdermal patches	Tablets, Oral solution Modified release (MR)	Tablets, Oral solution	
	Dose	5mg mane for 4 weeks Increase to 10mg mane	 1.5mg bd for 2 weeks Increase to 3mg bd for 2 wks Maximum 6mg bd Transdermal 4.6mg/24 hours for 4 weeks 9.5mg/24 hours for 6 mths Max 13.3mg/24 hours If treatment interrupted for more than 3 days retitration required 	5mg od for 1 week Increase to 10 mg for 1 week Increase to 15mg for 1 week Max 20mg od	Dementia Sustainabili Transform Plans Compete framewo	
	Side effects	Gastrointestinal: abdo pain, dyspepsia, nausea vomiting, diarrhoea, anorexia Constipation weight loss raised blood pressure Cardiac: Arrhythmias, hypotension Headaches, dizziness, fatigue Neurological: headache, dizziness, fatigue, insomnia, seizures Others: Urinary incontinence, muscle spasm				
	Rare side effects		es, rash, Hepatitis, pancreatitis, bladde ed vision, taste disturbance; tinnitus, h		Abnormal gait; confusion, hallucinations; heart failure; thrombosis; vomiting, seizures	Informat
	Cautions	Hx of Asthma, COPI	D, cardiac conduction abnormalities, p	eptic ulcers, seizures.	Hx of seizures	





12	ANTICHOLINERGIC BURDEN (ACB)	(3 OF 3)		
	Acetylcholine has a role in memory fur can have several adverse effects incluc be worse for people with dementia. Th anticholinergic burden (ACB).	ling sedation, cognitive impairr	nent, falls and delirium. These effe	ects may
	ACB Scales are a practical tool to estab used routinely to inform prescribing ch			should be
	A high score on an ACB scale is associ important to calculate the ACB for patients ACB to a minimum.			
	Wherever possible drugs should be ch cholinergic burden. If this is not possib preferred as they are likely to have a sig	le then anticholinergic drugs th	nat do not cross the blood-brain ba	
	In the table below alternative treatmen			СВ
	Drugs with anti-cholinergic properties	Indication	Alternative Treatments	
	Oxybutynin Tolterodine	Urinary incontinence	Trospium Darifenacin	
	Metoclopramide Cyclizine Prochlorperazine	Nausea	Ondansetron	
		Depression	0001	
	Amitriptyline Nortriptyline	Depression	SSRIs	
		To counteract extra-pyramidal side effects	SSRIs Trial without (only 10% of long-term uses need to re-start)	
	Nortriptýline	To counteract extra-pyramidal	Trial without (only 10% of long-	
	Nortriptýline Procyclidine	To counteract extra-pyramidal side effects	Trial without (only 10% of long- term uses need to re-start)	
	Nortriptýline Procyclidine Hyoscine hydrobromide Chlorphenamine Promethazine Hydroxyzine	To counteract extra-pyramidal side effects Hyper-salivation	Trial without (only 10% of long-term uses need to re-start) Pirenzepine Loratadine	
ack	Nortriptýline Procyclidine Hyoscine hydrobromide Chlorphenamine Promethazine Hydroxyzine Cyclizine Ranitidine	To counteract extra-pyramidal side effects Hyper-salivation Antihistamines	Trial without (only 10% of long-term uses need to re-start) Pirenzepine Loratadine Fexofenadine Omeprazole	Next

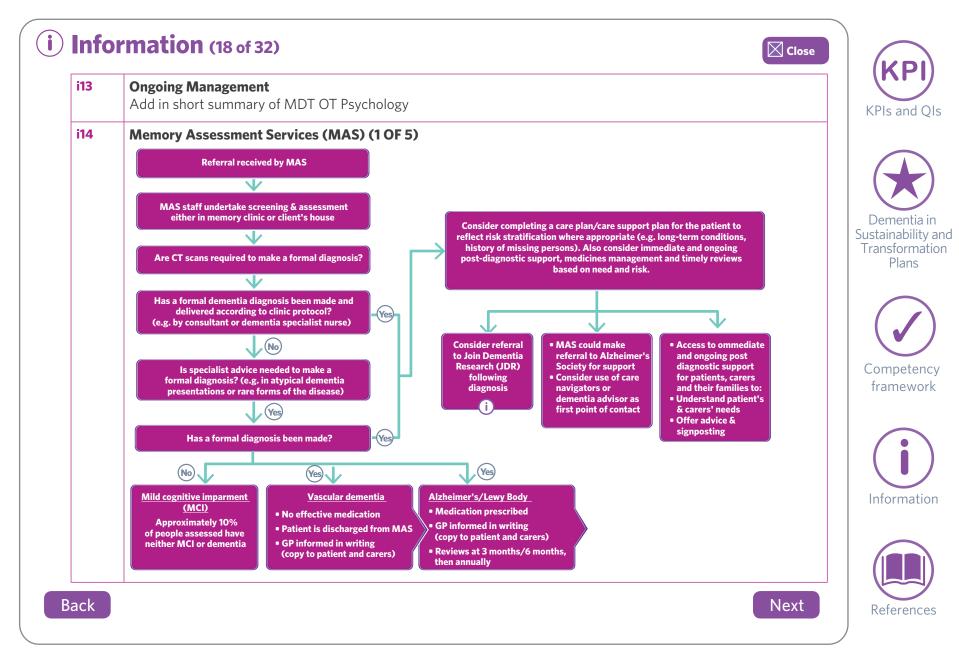
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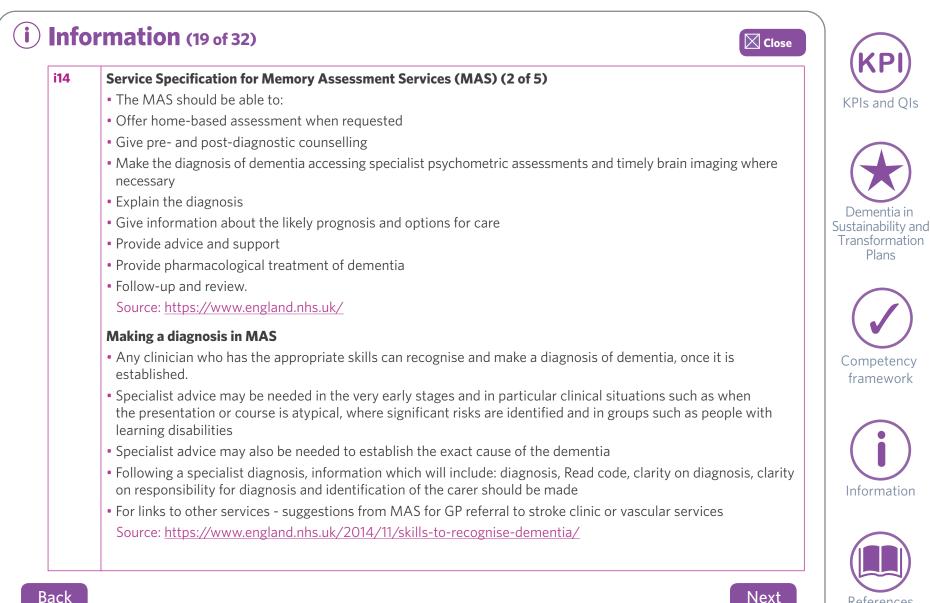


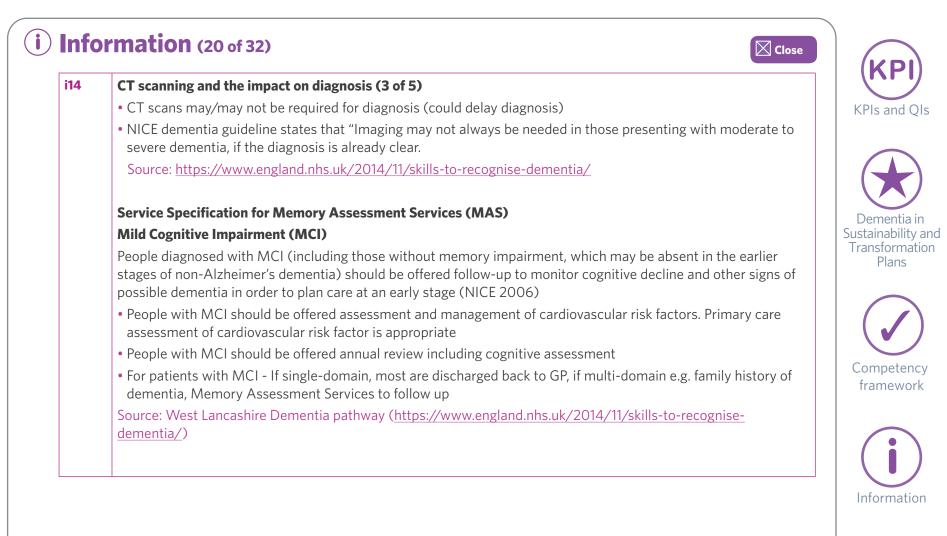




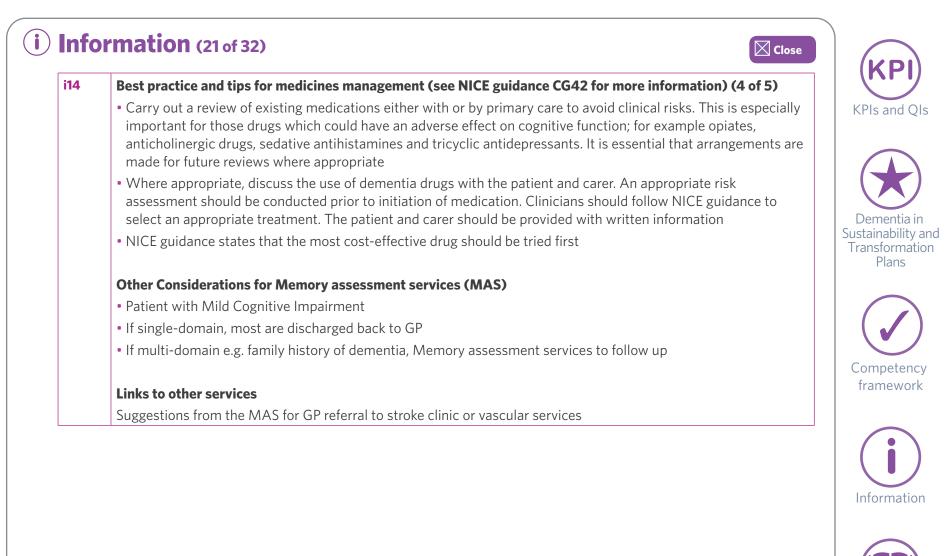
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i14	Service Specification for Memory Assessment Services (MAS) (5 of 5)	
	Annual Review	KPIs ar
	• MAS undertaking Annual review or Decisions around MAS passing over annual review process to GPs	
	Some GPs undertaking a 12 month review for the Quality and Outcomes Framework (QOF)	
	Links to other services	Demer
	Suggestions from the MAS for GP referral to stroke clinic or vascular services	Sustainal
i15	 Review annually As part of a 6 month or 12 month annual review a GP or suitably qualified clinician will invite a person living with dementia to discuss a care plan Review and understand diagnosis Additional psychological support Early intervention: drug and non-drug approaches Information provision Future care planning 	Pla
	A review might include: • Living with dementia • Cognition and medication • Physical health check • Risks and behaviours • Avoiding unplanned admissions • End of life.	Inform

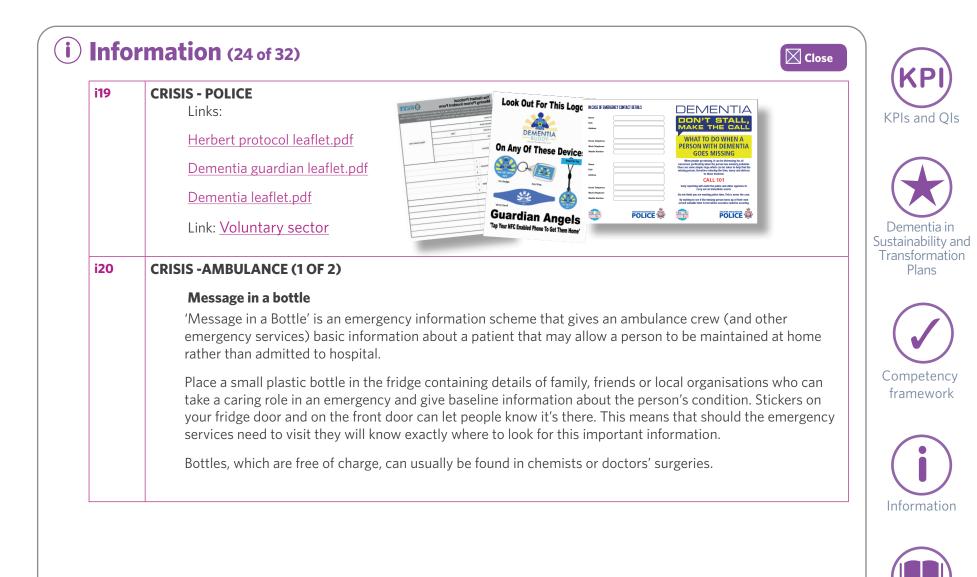




i16	Life Events to consider /NOT IN CRISIS Driving / Travel / moving care home /Legal POA	KPIs and QIs
i17	SUPPORTING WELL	
	Tips and best Practice for Supporting Well	
	Effective Communication	
	Advocacy and Empowerment	
	 Focus on capabilities not dependencies 	
	 Use of new technologies and Telemedicine 	Dementia in Sustainability and
	 Training and Support for staff and Families 	Transformation
	Treatment advice out of hospital	Plans
	Effective Signposting	
	Timely Reviews	
	• Telecare	
	Housing	
	Safety and Security	
	Education and better understanding of the condition can help support better patient care by	Competency
	directing patients, their carers and families to the appropriate services	framework
	 Clear Roles and Responsibilities needed for appropriate signposting - consider the various tiers 	
	of training and health and social care groups where appropriate.	
i18		
	A guide to symptom management in palliative care:	
	Link: https://www.yorkhospitals.nhs.uk/document.php?o=2360	Information
		I information

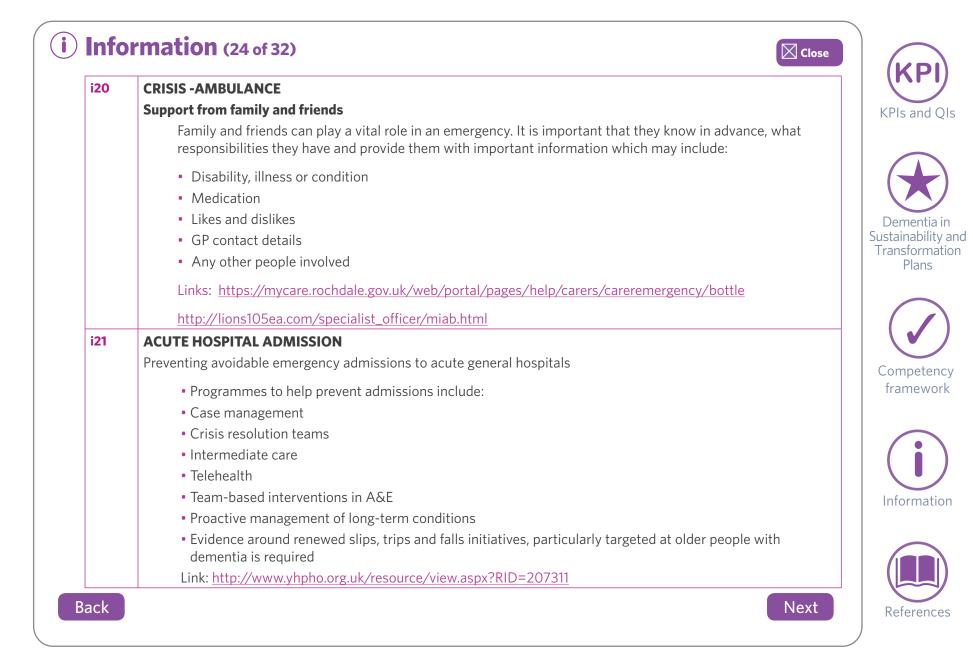


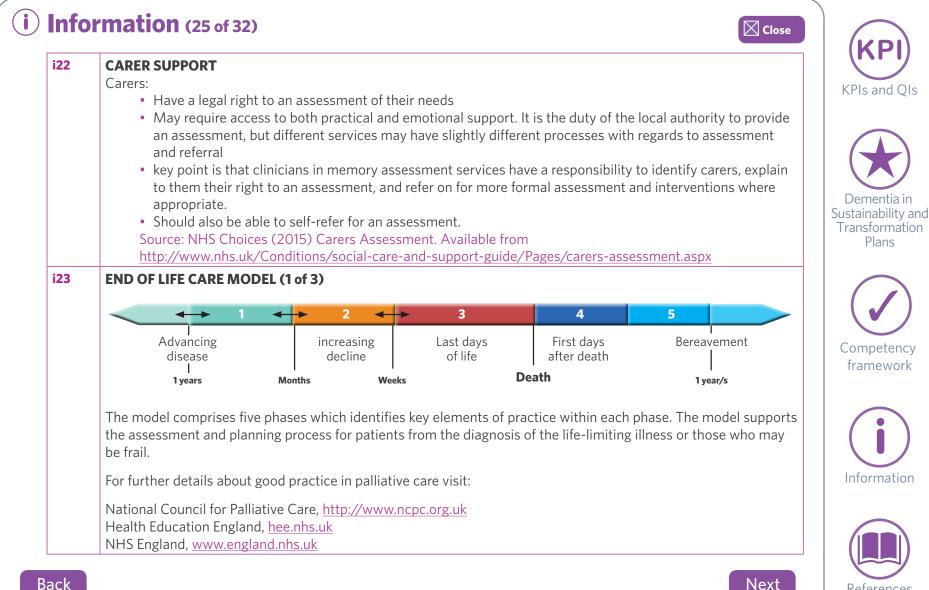
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References





23	END OF LIFE CARE MODEL	(2 of 3)			
	LAST YEAR OF LIFE Year/s	INCREASING DECLINE Months/Weeks	LAST DAYS OF LIFE Days	CARE AFTER DEATH 1 year/s	KPIs a
	 Patient identified as deteriorating despite effective management of underlying medical condition(s) Clear, sensitive communication with patient and those identified as important to them Person and agreed others are involved in decisions about treatment and care as they want Needs of those identified as important are explored, respected and met as far as possible Patient included on Supportive Care Record /GP Gold Standards Framework register and their care reviewed regularly Request consent to share information and create EPACCS record 	 Medical review All reversible causes of deterioration explored Clear, sensitive communication with patient and those identified as important to them Person and agreed others are involved in decisions about treatment and care as they want Needs of those identified as important are explored, respected and met as far as possible Prioritised as appropriate at Gold Standards Framework meeting On-going District Nurse support Agree on-going monitoring and support to avert crisis Holistic needs assessment 	 Medical review All reversible causes of deterioration explored Multidisciplinary Team agree patient is in the last days of life Clear, sensitive communication with patient and those identified as important to them Dying person and agreed others are involved in decisions about treatment and care as they want Agree on-going monitoring and support to avert crisis Advance Care Planning discussion offered or reviewed On-going District Nurse support ICD discussion and deactivation if not previously initiated 	 Nurse verification of death where indicated Certification of death Clear sensitive communication Relatives supported Department for Work & Pensions 011 Booklet; What to do after a death or similar Post death Significant event analysis Update Supportive Care Record/ Gold Standards Framework Register/EPaCCS with date and place of death Inform all relevant agencies; social care, Allied Health Professional, ambulance service, OOH, Specialist Palliative Care Team, equipment store 	Demer Sustainal Transfo Pla Compe frame
	ADRT - Advan DNACPR - Do	ce Decision to Refuse Treatment Not Attempt Cardio Pulmonary Resuscitation ronic Palliative Care Coordinating System	ICD - Implantable Cardioverte		

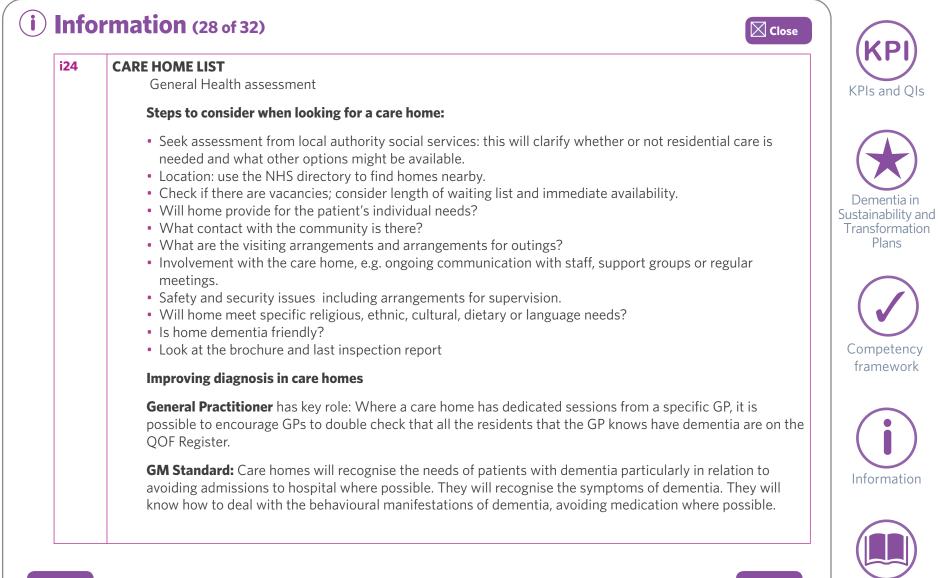
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	DEL (3 of 3)			
LAST YEAR OF LIFE Year/s	INCREASING DECLINE Months/Weeks	LAST DAYS OF LIFE Days	CARE AFTER DEATH 1 year/s	KPIs a
 Holistic needs assessmen Keyworker identified Identify when there is an opportunity to offer an Advance Care Planning discussion and/or refer or ADRT/PPC/MCA/ DNAC making a will Benefits review of patient and carer including Grant prescription exemption Provide information on Blu Badge (disabled parking) scheme Agree on-going monitorin and support to avert crisis Referral to other services Specialist Palliative Care OOH/NWAS updated including Advance Care P DNACPR ICD discussion if applicab 	 Keyworker Review or offer advance care plan, share information with patients consent Consider Continuing Health Care funding/DS1500 Equipment assessment Anticipatory medication prescribed and available DNACPR considered, outcome documented, information shared appropriately including ambulance service Out of Hours/NWAS updated including DNACPR status and Advance Care Plan Referral to other services e.g. Specialist Palliative Care Update EPaCCS Record as 		 Funeral attendance if appropriate Follow up bereavement assessment to those identified as important Referral of those identified as important to bereavement counselling services as required Staff supported 	Demen Sustainal Transfor Pla Compe frame

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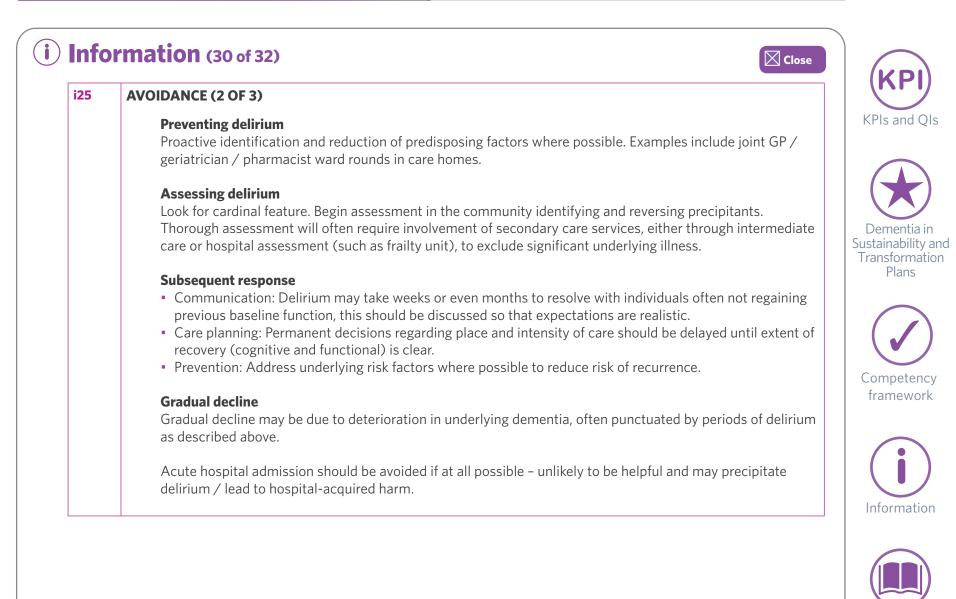




i25	AVOIDANCE (1 OF 3)	
	Cognitive and functional decline often coexist, posing a significant threat to independence. In people with dementia it is often possible to categorise this decline as acute or sub-acute, based on the time it has taken to evolve.	KPIs and QIs
	Acute decline: delirium	
	It is unusual for dementia to deteriorate suddenly, outside of rare conditions such as vCJD or the stepwise decline of vascular dementia. In the majority of cases an acute cognitive decline, hours to days or even short weeks, is likely to be due to delirium. Such change should trigger a thorough assessment, in order to identify and address acute precipitants (there will often be more than one) and predisposing factors.	Dementia in Sustainability and Transformation Plans
	In essence, in an individual at risk, almost any acute illness or change in environment may be enough to trigger delirium.	
	Common predisposing factors include but are not limited to:	
	1. Polypharmacy (particularly consider anti-cholinergic drug burden)	Competency
	2. Frailty	framework
	3. Dementia 4. Long-term urinary catheter	
	5. Chronic disease, especially neurological disease, i.e. Parkinson's disease.	
	Common precipitants include but are not limited to:	
	1. Infection (Caution: urinary tract infection is often over-diagnosed in this scenario)	
	2. Medication changes – particularly opiate / anti-cholinergic / sedative	Information
	3. Pain	
	4. Constipation	
	5. Urinary retention and urinary catheterisation 6. Electrolyte imbalance (Na, Ca, Glucose)	







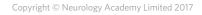


i25	AVOIDANCE (3 OF 3)	
	 Depending on the stage at which decline is recognised consider issues such as: Review treatment: Has dementia been subtyped and appropriate treatment initiated? If so, is it still required and appropriate? MDT working: Involve community support services and multi-professional teams. Autonomy over decision making. LPA (lasting power of attorney) / ACP (advance care planning) – may require specialist input. Priorities of care (patient / carer / diad): Where discordance is identified this may require specialist input (geriatrician / palliative care). Carer support: Maximising opportunity for care at home, where this is desired. Highlight: Importance of early recognition and action at this stage to prevent acute admission with associated harms. 	KPIs and C KPIs and C Dementia Sustainability Transforma Plans
i26	Associated narms.	
	Crisis management includes: • _Police • _Ambulance	Competer framewo
	 Also consider links to admission avoidance measures such as: Community based secondary care services such as ICT and CIC Community geriatrician, i.e. domiciliary visit 	
	 Community matron etc Frailty or admission avoidance units, to prevent A&E attendance 	Informati
	The specifics here are likely locality dependent, so may need to be linked to local services, region by region.	Informati





Post admission review should take place to consider: Has delirium resolved? Has function been regained? (ICT is usually involved in both of these assessments.) Are new care needs present, particularly considering the carer's needs and carer strain? Have risk factors for future crisis been addressed? (see above) Has prognosis deteriorated, if so: GSF (Gold Standards Framework)?ACP (advance care planning)? (End of Life Care Model) Staying well involves the following quality of life factors: Health Carer support Getting out and about Personal care and daily tasks House and home Managing medication Managing money Friends, family and people Communication Volunteering and work	
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Greater Manchester, Lancashire and South Cumbria Strategic Clinical Networks

Dementia Research

Guide to Dementia Research for Health and Social Care Staff across Greater Manchester, Lancashire and South Cumbria

Authors: GMLSC SCNs Dementia Network





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With special thanks to:

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Dr Amanda Thornton – SCN Dementia Clinical Lead

Dr Angela Parker

Dr Trevor Crawford

Join Dementia Research. Information can be found here

GMLSC SCNs Dementia Steering Group

Lancashire Care Foundation Trust

Thanks also to those who have commented and supported the further development of this guidance

Version	Date	Summary of changes	Ву





Introduction

GMLSC SCNs work across Greater Manchester, Lancashire and South Cumbria to deliver quality improvements for NHS patients.

Our Overall Aims are to:

- Reduce unwarranted variation in dementia care, health and well-being services
- Provide clinical advice and leadership to support decision making and strategic planning for dementia service providers across all settings
- Encourage innovation in how services are provided now and in the future for those living with dementia, their families and carers

Why is it so important to provide awareness around access and participation in Dementia Research?

In recent years, the needs of people with dementia, particularly in health and social care settings have been the focus of a great deal of work and developments.

Localities have become more aware that dementia is a key priority because:

- ✓ There are increasing numbers of patients with a dementia diagnosis. As at February 2016, latest dementia diagnosis data indicates that there are 63,821 individuals on Dementia registers (Lancashire and greater Manchester (34,518) and Cumbria and North East (29,303)
- There is recognition by localities in line with the national agenda to continue to improve the detection rates.
- The national agenda recognises that access to research can help improve care
- ✓ Memory Assessment Services across localities are experiencing increasing numbers of referrals to their services and this is a key service that could enhance this agenda

As a result, there is a need to ensure that research projects are promoted and accessed by people living with dementia and their carers across our stakeholder groups and organisations. This has been an important part of our focus in supporting the Prime Ministers challenge around recognizing the need:

"To connect people with dementia, their family members and carers to research studies taking place in their local area via join Dementia Research which will make participation in dementia research simple (pp.46)

"To enable all relevant staff to signpost interested individuals to research via 'Join Dementia Research" as appropriate (pp.39).

"For more research to be conducted in, and disseminated through care homes, and a majority of care homes signed up to the NIHR ENRICH 'Research Ready Care Home Network" (pp.34).



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To this effect, we have utilised evidence and best practice to develop this guidance that is able to flex across the boundaries of care on how and when to signpost patients, carers and families. It is anticipated that this engagement toolkit builds on the multiple resources available and accessible on the join dementia research website, in order to increase the numbers of people participating in research. The long term benefit is to build and enable a robust evidence base over time with regards to dementia treatment, care and services.

Aims of this Document

The aim of this document is twofold:

- ✓ To provide an 'introduction to the concept of research' so that that organisations that deliver dementia care and services can identify and recruit more volunteers across health and social care to participate in dementia research projects and studies.
- To build an informed workforce capable of navigating and supporting routes available and accessible within their various organisations, so that more individuals can get the help and support they need to participate in research that is available locally.

The guidance is aimed at Health and social care professionals to ensure that:

- Stakeholders deliver on the dementia priorities around the Prime Minister's 2020 challenge, the national Dementia Strategy (Department of health, 2009); join Dementia Research priorities, NIHR and Alzheimer's society.
- Research participation is enabled throughout the recently released NHS England Dementia Pathway Transformation Framework– The 'Well Pathway for dementia' including:
- Preventing Well Prevention and pre-diagnosis
- **Diagnosing well** Accurate, timely diagnosis and treatment and case finding in care/nursing homes
- Living Well Immediate post diagnosis period and ongoing Post-diagnostic support
- Supported Well Health and social care, advocacy, Hospital treatment etc.
- o Dying Well Palliative and End of life care, preferred place of Death

The intention is that building on these aims and objectives will enable GMLSC SCNs alongside our stakeholders, support the promotion and facilitation of access to research for the mutual benefit of the person and their families, researchers and future progress people.

Case for change

1. There are still gaps in accessing research across the country.

Marjanovic et al. (2015) identified some gaps in the UK dementia research system, noting that these were attributed to:

"... limited understanding of the cellular mechanisms that underlie dementia; insufficient clinician involvement in research; underinvestment in care-related research (e.g. in nursing, allied health professions and social-care fields); scope for improvement in the conduct of clinical trials (recruitment processes, incentives for clinicians to enrol patients, the accuracy of diagnosis, industry engagement); limited industry participation across diverse research and innovation challenges (drug-discovery efforts, the development of medical apps and assistive-living technologies); and insufficient focus on translational research".

The full report can be found here

2. Some research concerns identified by The Journal of Quality Research in Dementia <u>Issue 8</u> (lay version) are highlighted below:

- Research into the effects and benefits of palliative care for people with dementia is at an early stage.
- People with dementia may often be excluded from treatments in general hospital but what do we know about how well treatments work for them when they are made available?
- There is very little evidence available to assess the effectiveness of psychiatric treatments for people with dementia on general hospital wards
- ✓ There is a clear need for more research into what people with dementia think about their experience of hospital services. This is in addition to the need for research that will enable hospital staff to understand how best to provide services to people with dementia in a general hospital setting.

3. More recently, the new implementation plan 2020 for Dementia highlights Dementia research as a key area. It talks about offering "...more opportunities to participate in research, so that by 2018, 12% of people newly diagnosed with dementia each year will be registered on Join Dementia Research".

How this could work across the boundaries of health and social care

Dementia care and services can be potentially provided in primary care, secondary care or other services that fall within the health and social care environments.

The main priorities around participation in Research are consent & recruitment of people living with dementia, their carers and families. This will be different across the various settings highlighted below; however, one important point to note is that individuals should be asked if they are interested in any local or national research programmes in the first instance.

If there is a dementia advisor linked to the service, it is important that they work closely with the service and are involved in the diagnostic process (for example sitting in with the patient and carer when the diagnosis is being given) to offer



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immediate post diagnosis support and signposting. Research is one of the areas that individuals can be signposted to.

Also, during ACP discussions with a person with dementia, this is unlikely to be a one-off conversation or meeting that will cover everything. Therefore people in the early stages of dementia should be supported to make as many decisions as possible to ensure their future care and support best matches what they would want. For example, people can be asked if they would like to donate organs or bodies for research or to help others.

Primary care e.g. GP services	Secondary care e.g. Specialist memory assessment services (MAS)	Others settings e.g. Third sector, Voluntary organisations, social care
Suitable for all staff working in primary care settings such as GP surgeries, and care homes and who might be in contact with a person with dementia, their carer or family	Should be aimed at staff in hospital, acute or specialist memory. This is potentially the setting that will see majority of people with a diagnosed case of dementia and could potentially be a starting point to promote and facilitate access	Aimed at staff and individuals who will be working with or make contact with people with dementia, their carers and families.

<u>This guidance</u> can be used in various settings to act as an enabler, by providing a platform for staff working across these settings on when and how to promote research, as individuals with dementia are likely to be seen across these settings during the course of the disease progression.

How to get started

Education is a key enabler of this process, not only to ensure that staff provide and support individuals with the right information, but also to give them the confidence to facilitate and promote research priorities within their services. It is also seen as a means of promoting the right information already in existence and to obtain feedback on the process.

Health Education England (HEE, 2015) identifies three tiers and 4 staff groups relevant to education and training. The full framework can be found <u>here</u>

The Tiers of training identified are summarised below:

Tier 1	Tier 2	Tier 3
Dementia Awareness ('Essential information')	' Enhanced ' builds on Step 1	'Specialist ' builds on tiers 1 & 2.
Suitable for all staff working in health or social care; however, it does not provide sufficient information for staff who would be working regularly with people with dementia.	Should be aimed at staff in general healthcare settings or who are in regular contact with people with dementia. It can also be seen as a starting point for staff who will develop more specialist knowledge	Aimed at staff who will be working extensively with people with dementia and who are likely to be in a specialist or a decision making capacity.

The framework identifies the importance of recognising how the Core Skills Education and Training Framework relate to the different workforce groups within social care as summarised on the table below:

Groups	Social care workforce group
Group 1	All of the social care workforce – dementia awareness
Group 2	people working in social care who are providing personalised direct care and support to people with dementia
Group 3	Registered managers and other social care leaders who are managing care and support services for people with dementia



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This framework can be particularly useful in supporting the facilitation of staff within each staff group in enabling access and participation in research. Any training should therefore be focused on what works within the context of the setting where the enablement is likely to take place, including any other areas that staff has asked for. These include training staff and development of a training package to be utilised across various settings. The capacity needed to deliver it should also be considered.

Proposed pathways

The proposition on which these pathways are based is that primary care, secondary care and the third/voluntary sector will work in partnership as this is essential in ensuring that the use of available opportunities and specialist resources to enable access and participation in dementia research is maximized effectively. Also, Patients and their families may be seen across one or more settings during the course of the disease, therefore this minimizes the risk of missed opportunities where feasible.

Primary care

For most people with dementia will be seen within primary care where discussions with General Practitioners, Practice Nurses, District Nurses, Care workers and Social Workers, for example, might take place. This presents an opportunity to enable participation and access to locally available research, by ensuring that effective signposting to regarding research information, advice & support can effectively occur in the community setting.

Secondary care

Within secondary care, it is often not possible for every individual with dementia to access diagnostic and specialist services. As a result, concerted efforts need to be made within this setting to enable access to and participation in research by staffs that are most likely to come in contact with patients, particularly where they have not been referred from primary care to secondary care services. This means that there is a need for a whole system approach to ensure that opportunities are utilised where appropriate in the most effective manner to enable research participation.

Diagnosis does not only take place in Memory Assessment Service (MAS) – It is crucial that this part of the care pathway is understood so that patients and their carers are still able and encouraged to access research projects and activities

There are also opportunities at annual reviews within MAS to review participation and research priorities with patient, their carers and families



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Other Sectors

This could be implemented using a specification for community based dementia support services for dementia research. This could be targeted at voluntary or third sectors where patients, carers and families access dementia support and other peer group support services such as dementia café's, ageing well forums, Day centers etc. The aim is to reach out to as many potential recruits as possible who may or may not have been recruited within primary or secondary care. Also, these settings provide access to a hub of carers and family members who may be interested in joining Dementia research studies.

Proposed Check list for enabling dementia Research across various settings

	Core Element Description for Dementia research across GMLSC	Element met (Yes/No)	Notes/Narrative
1	Core Elements		
a.	Is Dementia research a key priority within your dementia strategy?		
b.	Do you have a dementia research Pathway or toolkit?		
С.	Do you have a dementia Pathway with a well-defined research element?		
d.	Do you have a named Dementia research key worker/ Dementia Adviser or Dementia research Nurse to facilitate the process?		
d.	Do you have a named dementia research lead?		
	Equity and effectiveness		
а.	Research Coordination – Do all patients have the same opportunities to access research activities and projects?		
b.	Are all patients being signposted to research activities and projects locally?		



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7	Signposting	
a.	Do You have an active signposting service for dementia patients, their carers and families?	
b.	Do you have information about local research activities and projects for that is easily accessible for patients, carers and their families?	
C.	Do you have access to website addresses and telephone numbers for local, regional and national research organisations?	

Method of Delivery

High quality resources are available for all levels of dementia resource as a result of current awareness that has taken place over the past few years. This has led to the provision of materials and advertisement resources aimed at people living with dementia, their carers and families. It is not clear however, which models have been most effective to date. What is known is that more promotion and facilitation is required to increase the numbers participating in line with the prime ministers challenge around research. The ambition will be to recruit more volunteers, match them to appropriate studies and increase participation to and above anticipated rates. This is the focus of join Dementia research. A recent report around this can be found <u>here</u>.

To re-iterate, Join Dementia research have a wealth of resources that can be utilised for various purposes, depending on delivery method chosen by the Organisation.

Anyone, with or without dementia, can register as a volunteer or sign-up for someone else, providing that you have their consent. Signing up is the first step in becoming involved in supporting vital research studies across the nation.

Join Dementia Research important Links

To access the volunteering information sheet and to know more about becoming a volunteer, please click <u>here</u>

For more information on how to sign up for yourself or someone else, please click <u>here</u>

To get in touch with Join Dementia research, please click here



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Face to a Face Delivery

Face to face delivery can support the recruitment of volunteers on the research registers. This can be utilised in any setting including memory assessment services to collect details pf patients that might be interested in participating in research studies. Individuals can then be matched to available studies taking place across the region. However, consent and how the information of patients is to be used should be made clear enough so that they understand and are aware of the protocols involved.

E – Resources

Locally available Dementia studies and research could be hosted on individual Organisation websites for access by patients with dementia, their carers and families.

Advertisement via Media and leaflets

This method of delivery provides access to a much wider population and can be used in any setting to create awareness around dementia research stu8dies and opportunities.

Face to Face	E-Resources/Advertisement/leaflets			
Pros				
Opportunity to ask questions	Opportunity for attendees to sight			
	advert on screen or stand			
One to one session	Visible to more than one individual			
Effective way to change attitudes	Effective way to change attitudes			
towards research participation	towards research participation			
Can be done at any time before,	Can be done at any time			
during or after consultation/activity				
Extensive resources available	Extensive resources available			
Able to evaluate whether the process	Able to evaluate whether the process			
has worked	has worked			
Co	ons			
Perceived as more time consuming	Difficult to establish whether			
	attendees have understood the			
	content			
Might incur additional resource –time	Not tailored to specific need and			
and staff cost	may need further clarification			
Reliance on staff knowledge and	Attendees may not have the			
understanding	opportunity to ask further questions			

Some of the pros and cons of each are detailed in the table below:



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Want to promote Join Dementia Research us in your local area and on Social media?

If you are willing to help Join Dementia Research spread the word in your locality, please click <u>here</u> for access to a wide range of resources

Routes to enabling Delivery

You may want to consider the following options:

a) Commissioned training to staff/individuals to enable participation in research

Organisations can provide the necessary knowledge and resources to allow those who have signed up to return to their settings and deliver workshops that will enhance participation and access to research. Following successful completion of the training, they could be provided with a certificate of attendance and detail their requirements moving forward. Delegates could also be given access to research experts and organisations for additional support as required.

This can be particularly useful for individuals or communities who provide dementia café services and drop in sessions within the community.

b) Use of Readily available resources

There are numerous organisations which deliver dementia resources and many of these are excellent. Join Dementia Research is a service aimed at people with dementia and their carers, but anyone with and without dementia over the age of 18 can sign up and people can register on behalf of someone else.

JDR work towards increasing the numbers of "...potential research participants and to recruit them more quickly, at the same time as informing volunteers of ongoing research opportunities"

c) Staff within primary and secondary care training to deliver information

Individuals could be identified within each setting who will be trained on specific research information and resources to ensure that the information provided remains relevant for the purposes of enhancing participation in research. This could be a research nurse or specific individual roles that report back to research nurses or experts within their localities.



d) Case studies

Evaluating if the chosen model has worked in the specific setting

Evaluation can be done on several levels depending on the size and structure of your Organisation and what you choose to measure. For example: if your aim from the training was to see improved satisfaction from people living with dementia and their families and carers – then measuring the number of people who have been referred as a result of the action of the Organisation might be a good start.

Appendix 1 – Dementia research evaluation Plan

Question	Response



The Herbert Protocol Missing Person Incident Form



There may be important pieces of information that you are able to provide the police in the event that the person you are caring for has gone missing. Try and have several copies of recent, close up photographs of the person, this may help the police when searching for them.

Full name			
Preferred name			
Date of birth		Age	
Ethnicity			Attach photo here
Current address			
	1		
Previous addresses	2		
	3		
Previous	1		
employment details and addresses	2		
	3		
Habits			
Hobbies			
Medication required			
Health condition(s)			
Blood type (if known)			
GP Name and address			

imes	Close
------	-------

General description e.g. hair colour, height, weight			
Distinguishing features e.g. scars, tattoos			
Has the person got a mobile phone?		If so, what is the number?	
Has the person got any mo	oney?	if so how much?	
Bank details			Bus pass; Name: Number:
Previous places found:			
Description of what the per	rson was wearing	; include colour, desig	ner label/brands
Shirt/Sweater			
Trousers/Skirt			
Outerwear e.g. coat, jacket			
Headwear			
Gloves			
Scarf			
Footwear			
Jewellery e.g. watch, rings			
Other			1
Time. date and location las	st seen:		
Risk Factors (please circle):	suicidal / depressi	ive / confused / alcohol	/ violent / other (describe)
Media release: Yes/No	On call ı	manager aware: Yes/N	Ло
Any other information that	may be of help to	the police	
Completed by			
Relationship to the person			
Date:			

Look Out For This Logo



On Any Of These Devices



Guardian Angels 'Tap Your NFC Enabled Phone To Get Them Home'

DEMENTIA DON'T STALL, MAKE THE CALL

WHAT TO DO WHEN A PERSON WITH DEMENTIA GOES MISSING

When people go missing, it can be distressing for all concerned, particularly when the person has memory problems. There are some simple steps which can be taken to help find the missing person, therefore reducing the time, worry and distress to those involved.

CALL 101

Early reporting will assist the police and other agencies to carry out an immediate search.

Do not think you are wasting police time. This is never the case.

By waiting to see if the missing person turns up of their own accord valuable time is lost where searches could be occuring.





INFORMATION TO HAVE TO HAND TO ASSIST POLICE IF PERSON GOES MISSING

DO NOT DELAY IN MAKING THE CALL TO THE POLICE

Having the following information available will assist the call handler to provide officers on patrol with an immediate description and other important information regarding the missing person. A police officer will still need to visit you to gain further details but this initial response is vital.

PERSONAL INFORMATION

Sex:	MALE / FEMALE	
Date of birth:		
leight:		
Build:		
lair colour/style:		
Glasses:	YES / NO	
Ethnic origin:		
Previous home addres	ss/addresses:	

11 How are they likely to get to these familiar places (i.e. type of transport or on foot?)

2 of 4

12 Details of close friends or relatives they may be visiting?

13 Health concerns:

14 Medication being taken:

15 Implications of NOT having medicines?

How mobile are they?
Day and time last seen:

18 Address last seen:

19 Clothing known or believed to be wearing:

20 Have they been missing before? YES / NO If so where were they found? (even if not reported to police)

21 Are they dressed for the weather/climate?

YES / NO

22 Do you have any other worries or concerns? YES / NO - If YES, please state below

23 If you have a recent photograph available please give this to the officer.

IN CASE OF EMERGENCY CONTACT DETAILS

Name	
Dob	
Address	
Home Telephone	
Work Telephone	
Mobile Number	
Name	
Dob	

Address

Home Telephone

Work Telephone

Mobile Number



Medications Reviewed in 2012 Update

Medications Added with Score of 1:	Medications Added with Score of 2:
Aripiprazole (Abilify™)	Nefopam (Nefogesic™)
Asenapine (Saphris™)	
Cetirizine (Zyrtec [™])	Medications Added with
Clidinium (Librax™)	Score of 3:
Desloratadine (Clarinex [™])	Doxylamine (Unisom™,
lloperidone (Fanapt™)	others)
Levocetirizine (Xyzal™)	Fesoterodine (Toviaz [™])
Loratadine (Claritin™)	Propiverine (Detrunorm [™])
Paliperidone (Invega™)	Solifenacin (Vesicare [™])
Venlafaxine (Effexor™)	Trospium (Sanctura™)

Medications Reviewed But NOT Added:
Fexofenadine (Allegra™)
Gabapentin (Neurontin™)
Topiramate (Topamax™)
Levetiracetam (Keppra™)
Tamoxifen (Nolvadex™)
Nizatidine (Axid™)
Duloxetine (Cymbalta™)

Criteria for Categorization:

Score of 1: Evidence from in vitro data that chemical entity has antagonist activity at muscarinic receptor.

Score of 2: Evidence from literature, prescriber's information, or expert opinion of clinical anticholinergic effect.

Score of 3: Evidence from literature, expert opinion, or prescribers information that medication may cause delirium.

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Use of the Anti-Cholinergic Burden (ACB) Scale may only be in accordance with the Terms of Use for the ACB Scale which are available at http://www.agingbraincare.org/tools/abcanticholinergic-cognitive-burden-scale.

To request permission for use, contact us at acb@agingbraincare.org.

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ANTICHOLINERGIC COGNITIVE BURDEN SCALE

Aging Brain Care

2012 Update

Developed by the Aging Brain Program of the Indiana University Center for Aging Research



Drugs with ACB Score of 1

Generic Name	Brand Name
Alimemazine	Theralen™
Alverine	Spasmonal™
Alprazolam	Xanax™
Aripiprazole	Abilify™
Asenapine	Saphris™
Atenolol	Tenormin™
Bupropion	Wellbutrin [™] , Zyban [™]
Captopril	Capoten™
Cetirizine	Zyrtec [™]
Chlorthalidone	Diuril [™] , Hygroton [™]
Cimetidine	Tagamet™
Clidinium	Librax™
Clorazepate	Tranxene™
Codeine	Contin™
Colchicine	Colcrys™
Desloratadine	Clarinex™
Diazepam	Valium™
Digoxin	Lanoxin™
Dipyridamole	Persantine™
Disopyramide	Norpace™
Fentanyl	Duragesic [™] , Actiq [™]
Furosemide	Lasix™
Fluvoxamine	Luvox™
Haloperidol	Haldol™
Hydralazine	Apresoline™
Hydrocortisone	Cortef [™] , Cortaid [™]
lloperidone	Fanapt™
Isosorbide	lsordil™, Ismo™
Levocetirizine	Xyzal™
Loperamide	Immodium™, others
Loratadine	Claritin™
Metoprolol	Lopressor [™] , Toprol [™]
Morphine	MS Contin™ , Avinza™
Nifedipine	Procardia™, Adalat™
Paliperidone	Invega™
Prednisone	Deltasone™, Sterapred™
Quinidine	Quinaglute™
Ranitidine	Zantac™
Risperidone	Risperdal™
Theophylline	Theodur™, UniphyI™
Trazodone	Desyrel™
Triamterene	Dyrenium™
Venlafaxine	Effexor™
Warfarin	Coumadin™

Drugs with ACB Score of 2

Generic Name	Brand Name
Amantadine	Symmetrel™
Belladonna	Multiple
Carbamazepine	Tegretol™
Cyclobenzaprine	Flexeril™
Cyproheptadine	Periactin™
Loxapine	Loxitane™
Meperidine	Demerol™
Methotrimeprazine	Levoprome™
Molindone	Moban™
Nefopam	Nefogesic™
Oxcarbazepine	Trileptal™
Pimozide	Orap™

Categorical Scoring:

 Possible anticholinergics include those listed with a score of 1; Definite anticholinergics include those listed with a score of 2 or 3

Numerical Scoring:

- Add the score contributed to each selected medication in each scoring category
- Add the number of possible or definite Anticholinergic medications

Notes:

- Each definite anticholinergic may increase the risk of cognitive impairment by 46% over 6 years. ³
- For each on point increase in the ACB total score, a decline in MMSE score of 0.33 points over 2 years has been suggested.⁴
- Additionally, each one point increase in the ACB total score has been correlated with a 26% increase in the risk of death.⁴

Aging Brain Care

www.agingbraincare.org

Generic Name	Brand Name
Amitriptyline	Elavil™
Amoxapine	Asendin™
Atropine	Sal-Tropine™
Benztropine	Cogentin™
Brompheniramine	Dimetapp™
Carbinoxamine	Histex [™] , Carbihist [™]
Chlorpheniramine	Chlor-Trimeton™
Chlorpromazine	Thorazine™
Clemastine	Tavist™
Clomipramine	Anafranil™
Clozapine	Clozaril™
Darifenacin	Enablex™
Desipramine	Norpramin™
Dicyclomine	Bentyl™
Dimenhydrinate	Dramamine [™] , others
Diphenhydramine	Benadryl [™] , others
Doxepin	Sinequan™
Doxylamine	Unisom™, others
Fesoterodine	Toviaz™
Flavoxate	Urispas™
Hydroxyzine	Atarax [™] , Vistaril [™]
Hyoscyamine	Anaspaz™, Levsin™
Imipramine	Tofranil™
Meclizine	Antivert™
Methocarbamol	Robaxin™
Nortriptyline	Pamelor™
Olanzapine	Zyprexa™
Orphenadrine	Norflex™
Oxybutynin	Ditropan™
Paroxetine	Paxil™
Perphenazine	Trilafon™
Promethazine	Phenergan™
Propantheline	Pro-Banthine™
Propiverine	Detrunorm™
Quetiapine	Seroquel™
Scopolamine	Transderm Scop™
Solifenacin	Vesicare™
Thioridazine	Mellaril™
Tolterodine	Detrol™
Trifluoperazine	Stelazine™
Trihexyphenidyl	Artane™
Trimipramine	Surmontil™
Trospium	Sanctura™

2



Yorkshire and the Humber Clinical Networks

Care Planning Yorkshire & the Humber

Nicola Phillis Nicola.Phillis@nhs.net

Care Planning Resources

- As part of a 6 month or 12 month annual review a GP or suitably qualified clinician will invite a person living with dementia to discuss a care plan.
 - Review and understand diagnosis
 - Additional psychological support
 - Early intervention: drug and non drug approaches
 - Information provision
 - Future care planning.

Care Planning Resources

- A review might include:
 - Living with dementia
 - Cognition and medication
 - Physical health check
 - Risks and behaviours
 - Avoiding unplanned admissions
 - End of life.

ents Living with Dementia Cognition & Medication Physical	health check Risks and beh	naviours AUA ES I	End of Life		Review of dementia advance	e care plan
ementia Annual Review					Date V Checked	
MENTIA QOF 15/16 REQUIRES FACE TO FACE CARE PLANNI rer to the review. e appointment should be with a suitably qualified clinician, not r nicians discretion which sections are completed. This template	ecessarily a GP. The care pl	lan is not required to	be carried out all at once			•
s good practice to allow patients to think about what they wish to eet. Where possible this should be given before and discusse	-	se give the patient th	e What makes a differei	nce' information		
What makes a difference	"What good looks like	"> 🕎 YHCS	Integrated Care Dementia F	athway		
All newly diagnosed patients should be considered for ACP to h ision making. ACPs should be reviewed annually to ensure the		YHCS Advance Car	-			
changed.	F patient 5 Wishes have	Review of dementia adv	ance care plan			
Review both the patient's and their carer's support needs and of	fer a carer's health check	Jump to Living with	Dementia page			
Review the patient's physical, emotional and medication needs n, nutrition)	(falls, continence, J	ump to physical heal	h check page		No previous values	
ssess the patient's behaviour, risks/safeguarding and driving r	eeds Jump to Risks	& behaviours page				
nitially consider at what stage of Dementia the patient is at to er nning	isure appropriate care	YHCS Dementia Glol	al Deterioration Scale			
Consider if the patient is suitable for inclusion on to the Avoiding ister? this will allow an MDT approach and 3 monthly follow up		Jump to Al	IA ES page			
inally, consider if the patient is approaching end of life and whe n inclusion in the gold standards framework & Palliative Care r		Jump to End of Li	e page			
Dementia care plan codes	Dementia care plan revie	ew code Rof X		•	Show recordings from other	▼ templates
Dementia care plan exception c QOF X	New Recall				Show empty recordings	

NHS

READ CODE 'HEAVY' VERSION

Residence Place of Residence Patient Personal Concerns and Goals - include details of the main issues and goals of the patient and carer Identifying personal goals Social Circumstances: Social Circumstances: include details of patient's social circumstances this could include details about their residential and accomodation circumstances eg; house/flat/stairs/aid adaptions eg: stair lifts etc Social circumstances Activities - include details of how the patient is engaging with family/friends/community Activities of everyday life Support Support: record who is caring for the patient and which services they are accessing. You can click on the preset button under the pencil button to add pre-configured options. Support services in place Under care of social services (ALKF) Receives help from voluntary agency (U) Mental health key worke Mental health key worke Under care of psychiatrist (XaA)	¥
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Receives help from voluntary agency (U Meals on wheels (13G7.)	
Meals on wheels (1367.)	6
Mental beath key worke Under care of psychiatrist (Xae	
Attending day centre (XaLLI) Mental health key worke Onder care of psychiadrist (XaA	
upport services required Home help needed (13664)	-
Diversion advocate (Ua2AK) Community Nursing Under care of continence nurse	•
Referral to Social Services (XaAey) Under care of community-base Referred for telecare (XaMic)	
Referred for telecare (XaMic) Under care of dietitian (XaARG)	-
Has a carer (who is)	
If the patient has a carer who is registered within the practice, they should be offered a Carers Annual Health Check. If the patient is registered elsewhe please advise them to contact their usual GP to discuss.	elationship
The Carers health check should be completed within the carer's record.	
You must record 'Carer of a person with Dementia - XaZ4h' to satisfy the Dementia DES.	
Patient is a carer 🔲 🖉 🙀 YHCS Carers Health Check 💿 NICE 💿 Alzheimers Society - Caring	

LIGHT VERSION

NHS

ntents Residence, care & support Medication Physical health check Risks and behaviours AUAES End of Life esidence, Care & Support sidence	Place of Residence
sidense	Date V Selection
sidence	
ce of Residence	
ecord patient's preferences about where they would prefer to be looked after if they became suddenly or seriously unwell:	
eferred place of care	
ocial Circumstances: includes details of patient's social circumstances this could include details about their residential and	
ccomodation circumstances eg; house/flat/stairs/aid adaptions eg: stair lifts, lives alone, housebound etc cial circumstances	
ipport .	
pport record who is caring for the patient and which services they are accessing.	
Mental Health, Domicillary Care, Meals on Wheels, Social Services, Other Healthcare Professionals	
er care of team	No previous values
arers	
Has a carer (who is) 🖉 🖉 Record Carer Patient's next of kin 🖉 🖉 Record Relationship	
he patient has a carer who is registered within the practice, they should be offered a Carers Annual Health Check. If the patient is registered elsewhere,	
ease advise them to contact their usual GP to discuss. In Carers health check should be completed within the carer's record.	
u must record Carer of a person with Dementia - XaZ4h to satisfy the Dementia DES.	
	Show recordings from other templates
Patient is a carer Image: Carers Health Check YHCS Image: Nice Alzheimers Society - Caring	Show empty recordings
Information Print Suspend Ok Cancel	

	4 of 10
Close Contents Living with Dementia Cognition & Medication Physical health check Risks and behaviours AUA ES End of Life	+ 01 10
Cognition & Medication	
Please consider any medication issues that may adversely effect cognitive functioning e.g. >4 medications, anti-cholinergics, antipsychotics,	•
psychotropic, sleeping tablets. Medication review done	•
Any observed changes in memory/orientation (eg getting lost)/recognising familiar people	
Cognitive function observations	
Compliance Drug compliance checked	
Compliance issues discussed with patient	
Drug compliance C Drug compliance good (8B3E.) O Drug compliance poor (Xalwn)	~
Understanding C Patient understands why taking all medication (XaJkW) Vess dispensed monitored dosage system C Patient does not understand why taking all medication	
Antipsychotics	
Antipsychotics should be used with extreme caution and consider referral to OP CMHT prior to use.	
When used antipsychotics should be time limited and regularly reviewed (at least every three months)	
THCS Antipsychotics in Older People	
Antipsychotic medication review	
Acetylcholinesterase inhibitor (AChEI) Memantine Review patient for side effects of headache, dizziness, drowsi	iness
Review patient for side effects of diarrhoea, headaches, fatigue. No need to monitor pulse rate or BP but may need to decreas	
Check pulse and BP, consider stopping if low. in renal impairment	
Jump to record pulse and BP	
Contents Living with Dementia Cognition & Medication Physical health check Risks and behaviours AUA ES End of Life	
Physical Check	
BP mmHg Pulse b	
Smoking Status Advice on smoking Alcohol int	
Height Meight Kg BMI	
General wellbeing	

General wellbein	g	
Mobility	Fully mobile (13C1.) Continence Continence Mobile outside with aid (13C2.) Incontinence of faeces (XE0rG) Mobile in home (13C3.) Urinary incontinence (1A23.) Needs walking aid in home (13C4.) Double incontinence (X30C5) Confined to chair (13C5.) Edd-ridden (13C6.)	•
Falls	At risk of falls (XalSz) Recurrent falls (XalGP) Multidisciplinary team falls assessment d At risk of osteoporotic fracture (XalTO)	
Influenza, Tetanus and Pneumococcus Status		
Referral made t	Image: Constraint of the section of	

5 of	1
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se		5 of 10		
	Y YHCS Dementia Annual Review Care Planning (QOF)			
1	Contents Living with Dementia Cognition & Medication Physical health check Risks and behaviours AUA ES End of Life			
	Risks, Behavioural & Psychological needs			
	eg: bored, frustrated, withdrawn			
	Mood/anxiety/depression			
	Adult protection issues			
	Vulnerable adult			
	Bradford Guidelines: Stadford Safeguarding Adults Street States Street S			
	Behaviours that challenge Preeining agricated (Carby) Consider early referral to OP CMHT & Care Home Liaison teams Verbal aggression (X7659) Self-neglect (X766C) Referral to: Wandering (X75ym) Inappropriate sexual behaviour (X7673) Verbal aggression (X7673)			
	Driving			
	Dementia is a condition that you need to tell the Driver & the DVLA about			
	Driving status			
	Patient advised about driving Patient advised to inform DVLA Patient advised to inform DVLA Patient advised to inform insurance company Patient advised to inform DVLA Patient advised to inform DVL			
	OVLA Form O Alzheimers Org - Driving & Dementia			
	Risks Click here to print information for the patient to take			
	Risks - please select all that apply Risk of self neglect (Xalv1) At risk of falls (XalSz) Drug compliance poor (Xalwn)			
	High risk patients may benefit from inclusion onto the Avoiding Unplanned Admissions ES register Jump to AUA ES page			
		1		
	YHCS Dementia Annual Review Care Planning (QOF)			
	Contents Living with Dementia Cognition & Medication Physical health check Risks and behaviours AUAES End of Life			
Is your patient suitable for the Avoiding Unplanned Admission ES?				
The Avoiding Unplanned Admission ES allows a more proactive MDT approach to care, with regular care planning reviews every 3 months. Patients diagnosed with more moderate and severe dementia often benefit.				
Patient identified as At Risk of Unplanned Admission. Tick the box below to add the patient to the Case Management register.				
	Admission avoidance care started			
Named accountable GP & Clinical Co-ordinator				

Named accountable GP & Clinical Co-ordinator			
Please assign any patients onto the Case Management Register with a GP using Relationships. NB: All patients over the age of 75 should already have a named GP assigned.	Record GP		
Where appropriate you may wish to assign the patient with a Clinical Co-ordinator	Record Clinical Coordinator		
Informing patient of named accountable general practitioner			
Avoiding Unplanned Admissions Care Plan			
Record Sharing			

palliative care planning YHCS Dementia Staging Tool

GSF Prognostic Indicators for the Dementia	
Triggers to consider that indicate that someone is entering a late •Unable to walk without assistance and •Urinary and faecal incontinence, and •No consistently meaningful conversation •Unable to do Activities of Daily Living (ADL) •Barthel score <3	r stage are: Plus any of the following: •Weight loss •Urinary tract Infection •Severe pressures sores - stage three or four •Recurrent fever •Reduced oral intake •Aspiration pneumonia
GSF Planning	
This template covers end of life decisions and anticipatory care bu	It it is not only for patients in the last days of life. Please consider filling it in
and discussing the issues embedded within where capacity may b	It it is not only for patients in the last days of life. Please consider filling it in be impaired (or is likely to become impaired) or where health is anticipated to tation status, preferred place of care, lasting power of attorney and advance
and discussing the issues embedded within where capacity may b deteriorate rapidly in the next few years. Areas covered are resuscit statements and decisions to refuse treatment	be impaired (or is likely to become impaired) or where health is anticipated to
and discussing the issues embedded within where capacity may b deteriorate rapidly in the next few years. Areas covered are resuscit statements and decisions to refuse treatment	be impaired (or is likely to become impaired) or where health is anticipated to tation status, preferred place of care, lasting power of attorney and advance

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Yorkshire and the Humber Strategic Clinical Networks

Patient held care plan

- At the end of the review the GP or clinician will print of • a patient held care plan
- Still in development •
- From you perspective what should this include?
- What should not be included?
- What format should it be in?
- What would be useful to have in advance of the • review?



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	Patient Name:	Mouse Micky Mr	
			wo
		te: 10 Jul 2015	
	Dementia	a Care Plan	
+			
Mouse Micky Mr		NHS Number:	
Date of Birth:	25 Apr 1965	Gender: Male	
Language:	language not specified		
CONTACT DETAILS			
Current Home	Address: 7 Park Top Cottages Bingley	i	
	West Yorkshire		
	BD16 3DB		
Mobile Tel. (pre	· · · · · · · · · · · · · · · · · · ·		
Home Tel:	01274 555 5555		
REGISTRATION DETA	ALL C		
Practice:	425		
Review Date:			
THIS IS WHAT WE	KNOW ABOUT YOU		
Your concerns and	goals g personal goals, personal goals text		
10 Jul 2015, Identifying	g personal goals, personal goals text		
Your social circums	tance and activities		
	umstances, social circs text		
	of everyday life, activities text		
10 Jul 2015, Lives in ov 10 Jul 2015, Has a <u>car</u>			
10 Jul 2015, Has a gais	g, carername		
10 Jul 2015, Patient's r	next of kin, <u>NOK freetext</u>		
SURNAME, Nok			
This is support you	raceiva		
This is support you 10 Jul 2015, Attending			
10 Jul 2015, Under car			
10 Jul 2015, Under car			
10 Jul 2015, Patient th	emselves providing care		
10 Jul 2015, Under car			

THIS IS WHAT WE FOUND OUT TOGETHER

These are the findings of our physical health check

10 Jul 2015, Never smoked tobacco 10 Jul 2015, Alcohol intake 0 10 Jul 2015, Vulnerable adult 150 / 90 mmHg 10 Jul 2015, O/E - weight, 52 Kg 10 Jul 2015, O/E - height, 1.54 m 10 Jul 2015, Body mass index - observation, 21.93 Kg/m² 10 Jul 2015, Body mass index - observation, 21.93 Kg/m² 10 Jul 2015, Mobile in home 10 Jul 2015, Mobile in home 10 Jul 2015, Recurrent falls 10 Jul 2015, Incontinence of faeces

These are the medication you are on Current Acute Issues:

Current Repeat:

These are the results of your medication review

- 10 Jul 2015, Drug compliance good 10 Jul 2015, Patient understands why taking all medication 10 Jul 2015, Compliance issues discussed with patient
- 10 Jul 2015, Drug compliance checked

This is what you told us about how your memory is working 10 Jul 2015, Cognitive function observations, cog obs text

This is what you told us about your mood 10 Jul 2015, Level of mood, mood text

These are the risks that you and your carer are concerned about 10 Jul 2015, Drug compliance poor 10 Jul 2015, Risk of <u>self neglect</u> 10 Jul 2015, Self-neglect 10 Jul 2015, Wandering 10 Jul 2015, Inappropriate sexual behaviour 10 Jul 2015, Feeling agitated 10 Jul 2015, Verbal aggression 10 Jul 2015, Physical aggression

This is what you have told us about your driving 10 Jul 2015, Does drive a car



These are the future decisions in your Advance Care Plan Resuscitation discussed with carer, 10 Jul 2015

Resuscitation discussed with caller, 10 Sul 2015

WHAT WE HAVE DECIDED AND DONE TOGETHER

Your referrals and next step for your practice/GP

10 Jul 2015, Referral by continence nurse

10 Jul 2015, Referral to occupational therapy service

10 Jul 2015, Referral to physiotherapist

10 Jul 2015, Referral to Social Services

10 Jul 2015, Drug compliance aid requested

10 Jul 2015, Referral to dietitian

10 Jul 2015, Referral to psychiatrist for the elderly mentally ill

What advice we have given you

10 Jul 2015, Advice on smoking 10 Jul 2015, Patient advised to inform insurance company 10 Jul 2015, Patient advised about driving 10 Jul 2015, Education : Implications to license

What reviews we have done together

10 Jul 2015, Medication review done 10 Jul 2015, Antipsychotic medication review 10 Jul 2015, Patient advised to inform DVLA

ALL KNOWN RELATION SHIP

GP: SURNAME, Dr , 5434325420542

Clinical Coordinator: CO-ORDINATOR, Clinical, 213415641254187

Next of Kin: SURNAME, Nok, 0214564231864

Power of Attorney:

SENSITIVITY & ALLERGY SUMMARY



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LAR OF CAR

What could really make a difference?

Name:]
Completed with:	Ĵ
Date:]

This leaflet is designed to help you and your family and carers think about how things are working for you at the moment and what ideas you have that could really make a difference for you. Please take your time to think through the questions and write down any thoughts and ideas you have. You can then discuss these ideas with your key worker when you review your care and support package.

How are you doing?

\odot	
l am	
coping fine	

l am doing OK



I am not coping so well

+

•					
These are some things that people sometimes want to talk about. Circle any that are important to you.					
chere any that are	important to you	•			
Bathing and Hygiene	My current care	Supporting my family/carers	Feeling lonely		
Finances	Lack of control	Feeling hopeless	Pain		
Feeling low or stressed	Feeling scared	Eating and drinking	Mobility		
Taking medication	My future health	Alcohol	Physical activity		
Keeping warm	My memory	Hearing	Smoking		
Staying steady	My weight	Slowing down	My sight		

Close	10 of 10
©Year of Care	
What is important to you?	
What is working well? What isn't working so well?	
What needs to change?	
What ideas do you have?	
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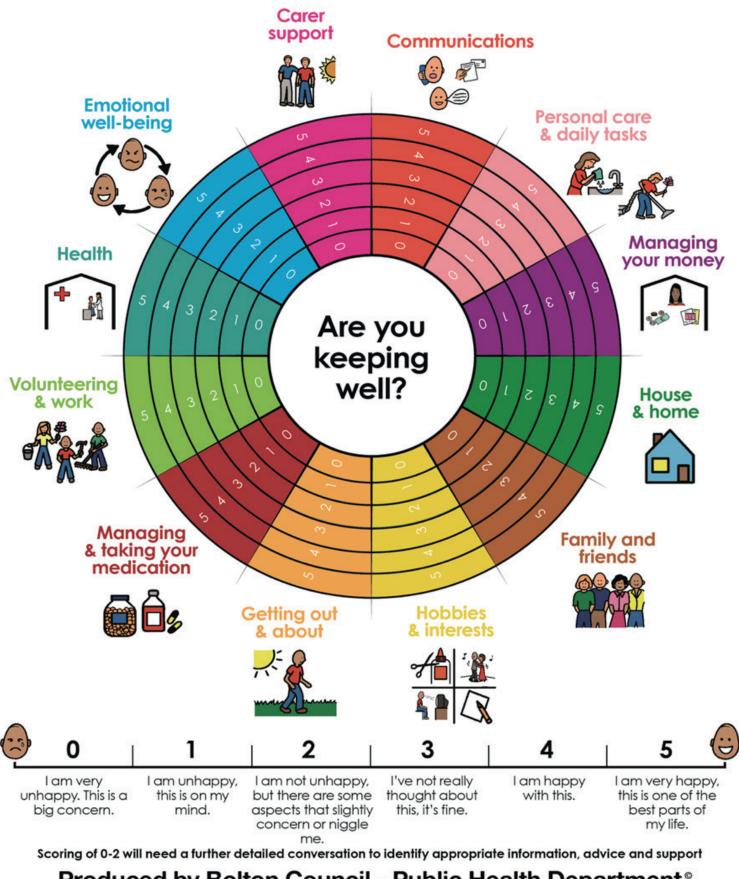






Integrating Heath & Social Care Quality of life wheel

Using the scale at the bottom of this page, tell us how happy or unhappy you are using the key categories from the quality of life wheel. Please rate these from 0-5.



Produced by Bolton Council - Public Health Department*