Greater Manchester and Eastern Cheshire
Strategic Clinical Networks

Dementia interactive care pathway toolkit

ENTER

Date of preparation: 3 February 2017

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 -

KPI **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 HSCIC website.

⊕ **Additional information** gives more detail on a specific part of the pathway - anything from national guidance to activity needed, to commissioning recommendations.

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✓ Competency framework

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★ **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

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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Dementia United, www.dementiaunited.net
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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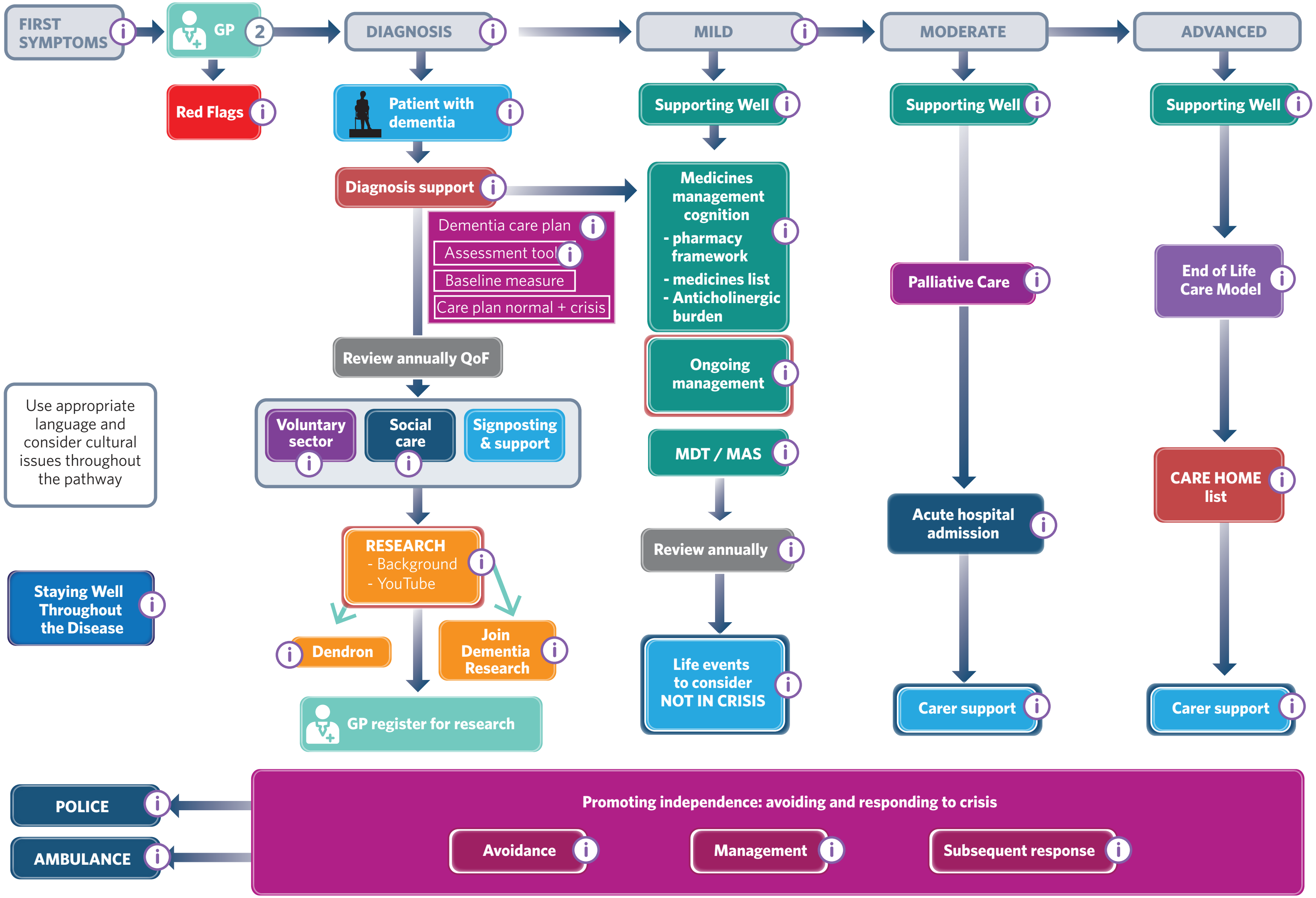
Overview Pathway



FIRST SYMPTOMS → GP 2 → DIAGNOSIS → MILD → MODERATE → ADVANCED

GP → Red Flags

DIAGNOSIS → Patient with dementia → Diagnosis support → Review annually QoF

Dementia care plan
Assessment tool
Baseline measure
Care plan normal + crisis

Voluntary sector
Social care
Signposting & support

RESEARCH
- Background
- YouTube

Dendron
Join Dementia Research
GP register for research

MILD → Supporting Well → Medicines management cognition
- pharmacy framework
- medicines list
- Anticholinergic burden

Ongoing management
MDT / MAS
Review annually
Life events to consider NOT IN CRISIS

MODERATE → Supporting Well → Palliative Care → Acute hospital admission → Carer support

ADVANCED → Supporting Well → End of Life Care Model → CARE HOME list → Carer support

Use appropriate language and consider cultural issues throughout the pathway

Staying Well Throughout the Disease

POLICE
AMBULANCE

Promoting independence: avoiding and responding to crisis
Avoidance
Management
Subsequent response

NHS Dementia Well pathway Framework Domains

1. Preventing Well
2. Diagnosing Well
3. Supporting Well
4. Living Well
5. Dying Well

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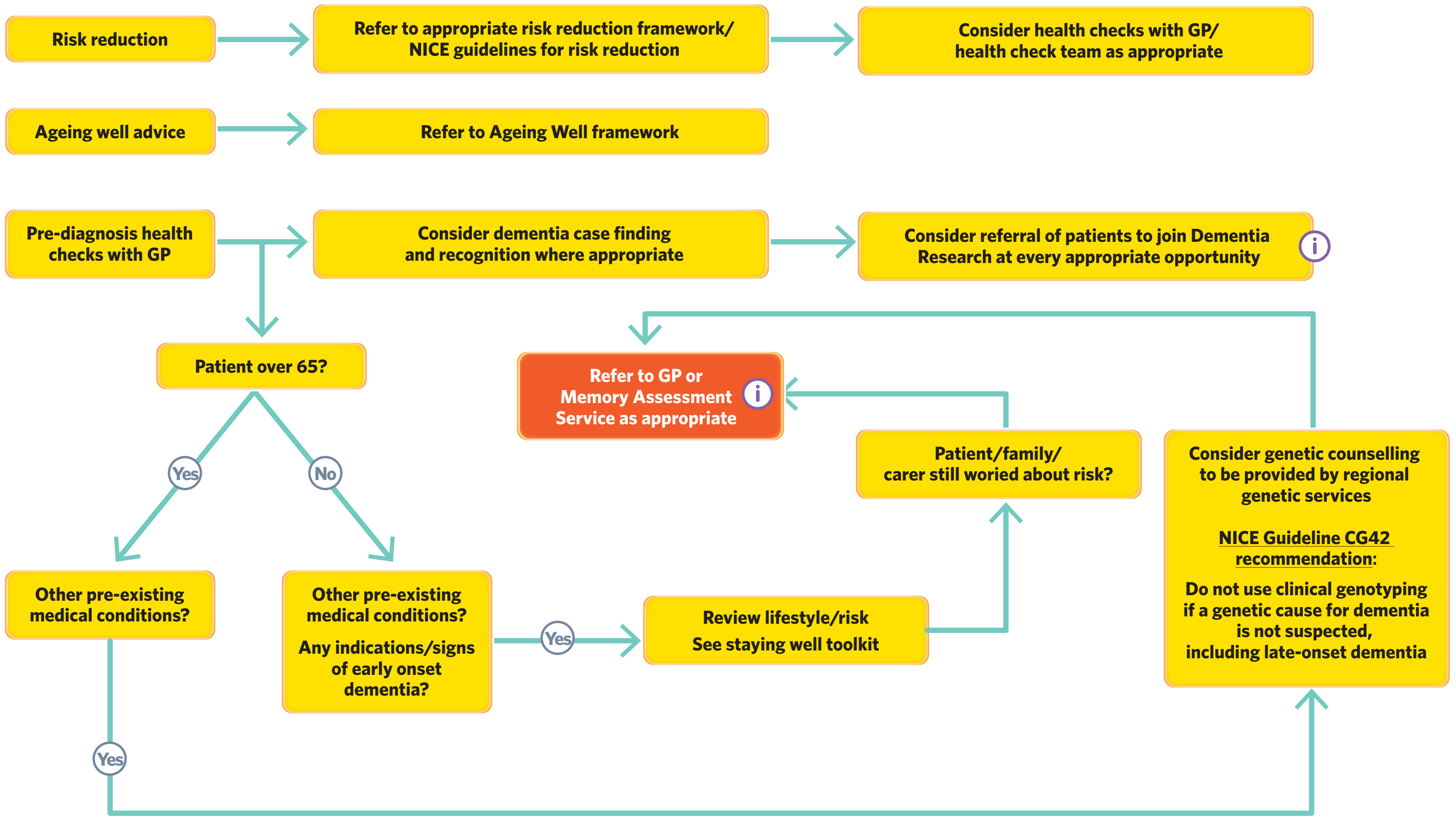

Risk reduction → Refer to appropriate risk reduction framework/ NICE guidelines for risk reduction → Consider health checks with GP/ health check team as appropriate

Ageing well advice → Refer to Ageing Well framework

Pre-diagnosis health checks with GP → Consider dementia case finding and recognition where appropriate → Consider referral of patients to join Dementia Research at every appropriate opportunity ⓘ

Pre-diagnosis health checks with GP → Patient over 65?

- Yes → Other pre-existing medical conditions?
  - Yes → Consider genetic counselling to be provided by regional genetic services
- No → Other pre-existing medical conditions? Any indications/signs of early onset dementia?
  - Yes → Review lifestyle/risk See staying well toolkit → Patient/family/ carer still woried about risk? → Refer to GP or Memory Assessment Service as appropriate ⓘ

Consider genetic counselling to be provided by regional genetic services

NICE Guideline CG42 recommendation:

Do not use clinical genotyping if a genetic cause for dementia is not suspected, including late-onset dementia

Consider genetic counselling → Refer to GP or Memory Assessment Service as appropriate

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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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Risk reduction:

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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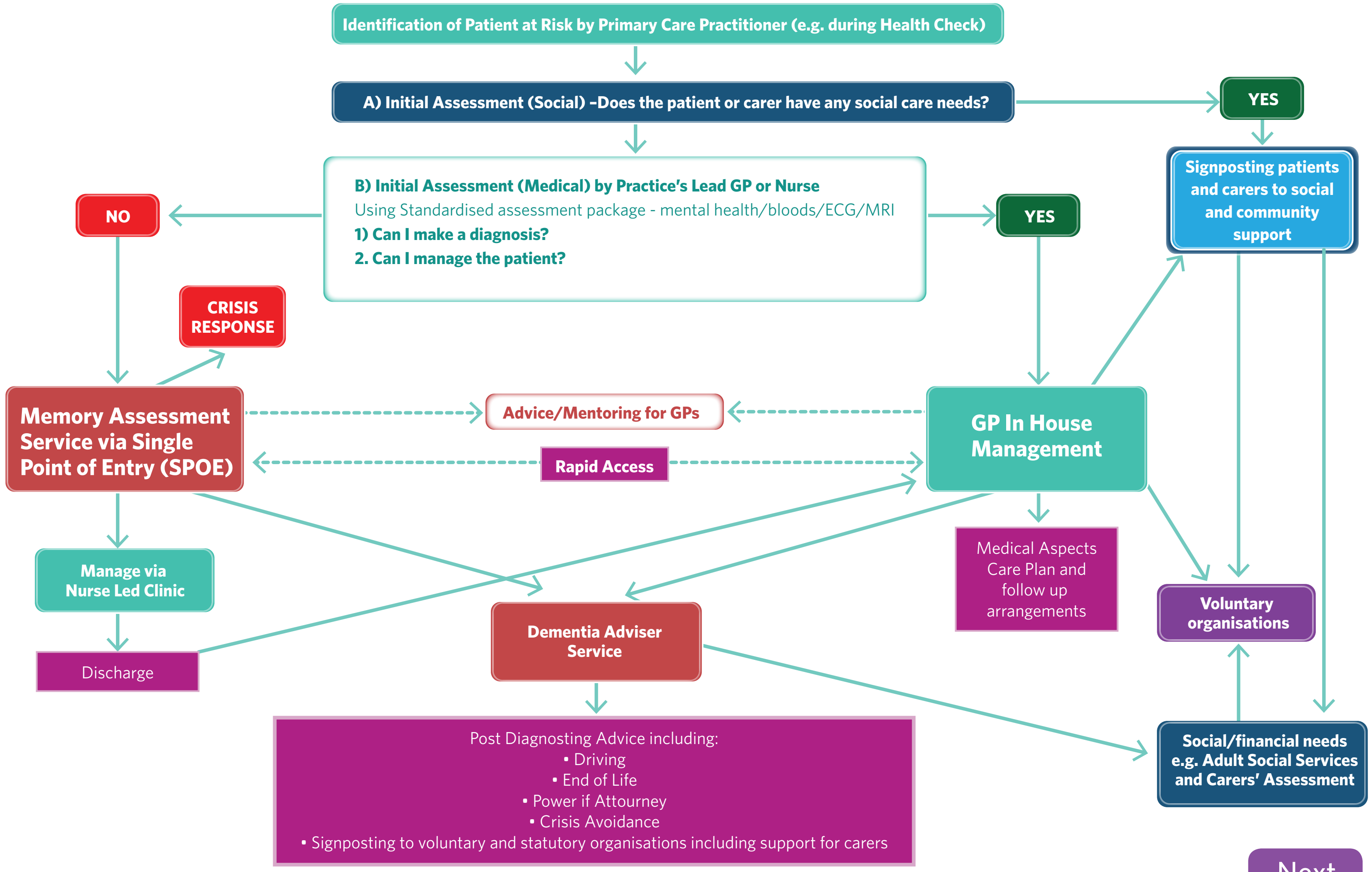
2 DIAGNOSING WELL (1 of 3)

GP – Bury diagnosis pathway



Identification of Patient at Risk by Primary Care Practitioner (e.g. during Health Check)

A) Initial Assessment (Social) –Does the patient or carer have any social care needs?

YES

Signposting patients and carers to social and community support

B) Initial Assessment (Medical) by Practice's Lead GP or Nurse
Using Standardised assessment package - mental health/bloods/ECG/MRI
1) Can I make a diagnosis?
2. Can I manage the patient?

NO

YES

CRISIS RESPONSE

Memory Assessment Service via Single Point of Entry (SPOE)

Advice/Mentoring for GPs

Rapid Access

GP In House Management

Manage via Nurse Led Clinic

Discharge

Dementia Adviser Service

Medical Aspects Care Plan and follow up arrangements

Voluntary organisations

Social/financial needs e.g. Adult Social Services and Carers' Assessment

Post Diagnosting Advice including:
- Driving
- End of Life
- Power if Attourney
- Crisis Avoidance
- Signposting to voluntary and statutory organisations including support for carers

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Diagnosing Well Standards 2, 3, 4, 5 (developed by Dementia United)

- Each locality will achieve dementia diagnosis rates comparable with the top 20% nationally
- People receiving an initial assessment and diagnosis will feel this is timely
- People will receive a comprehensive assessment of mental and physical health issues as part of the diagnostic process and at regular intervals subsequently
- People will be offered medication in line with NICE guidelines
- Measure:
- Dementia Diagnosis

Source: NHS England, Monthly (https://www.england.nhs.uk/mentalhealth/dementia/monthly-workbook/)

Care homes

- Not just for GPs, but everyone's responsibility. Information often "hidden" in patient notes
- Outcome of referrals to memory clinic - diagnosis may be hidden in the text
- Always remember referrals to: neurologist (younger / atypical), geriatrician (co-morbidities), learning disability services
- Remember to include new residents in any checks
- Down Syndrome: Dementia onset 35 years; 50% have dementia at 60 years
- To improve 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.

General practitioner

- Where a care home has dedicated sessions from a specific GP, it is possible to encourage GPs to double check that all the residents that the GP knows has dementia are on the quality and outcomes framework (QOF) register
- Enhanced services linkage
- Initiatives to improve diagnosis in care homes can support the existing focus of aligning GP practices to specific homes

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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

- 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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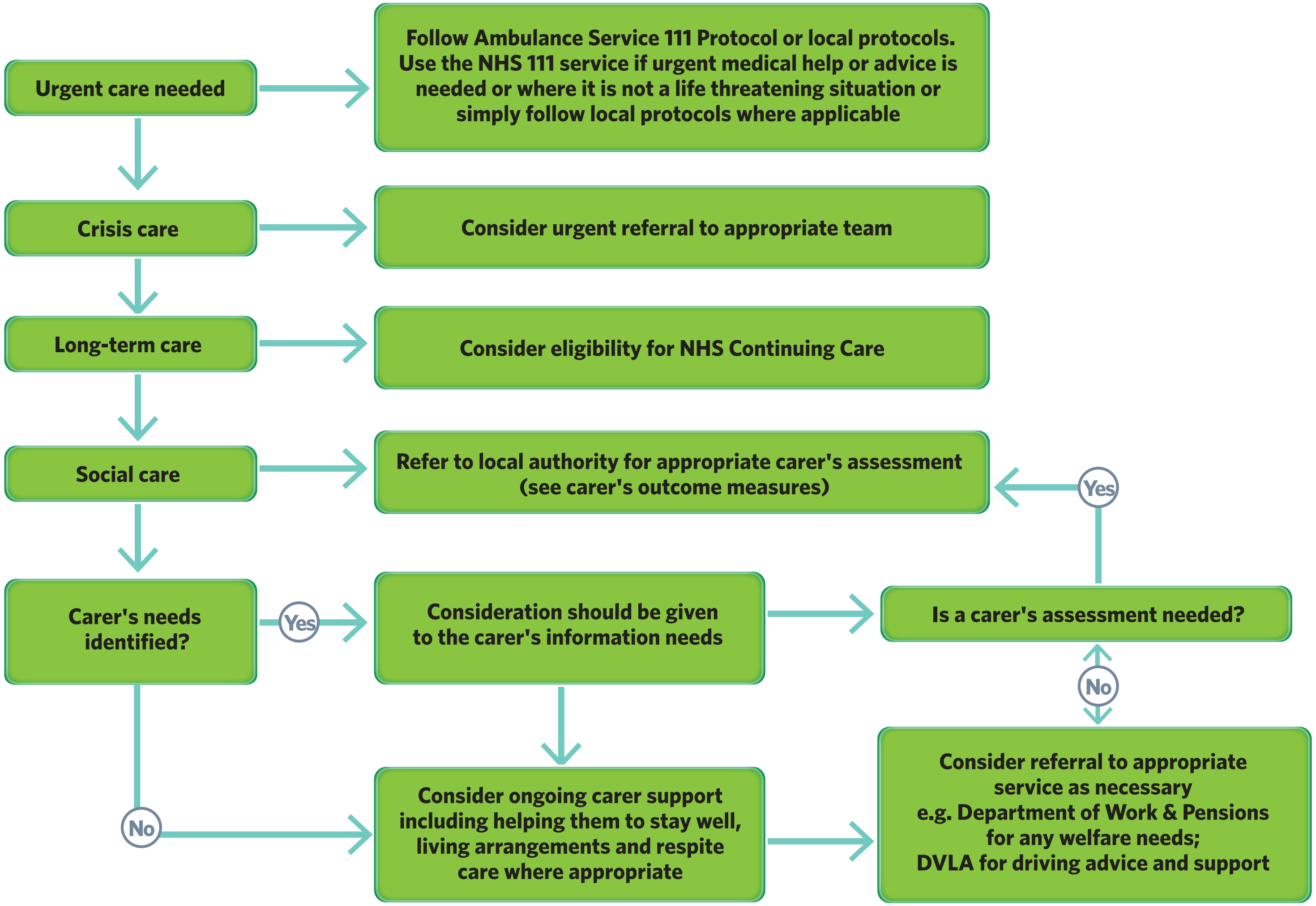

Urgent care needed → Follow Ambulance Service 111 Protocol or local protocols. Use the NHS 111 service if urgent medical help or advice is needed or where it is not a life threatening situation or simply follow local protocols where applicable

Crisis care → Consider urgent referral to appropriate team

Long-term care → Consider eligibility for NHS Continuing Care

Social care → Refer to local authority for appropriate carer's assessment (see carer's outcome measures)

Carer's needs identified?

- Yes → Consideration should be given to the carer's information needs → Is a carer's assessment needed?
  - Yes → Refer to local authority for appropriate carer's assessment (see carer's outcome measures)
  - No → Consider referral to appropriate service as necessary e.g. Department of Work & Pensions for any welfare needs; DVLA for driving advice and support
- Consideration should be given to the carer's information needs → Consider ongoing carer support including helping them to stay well, living arrangements and respite care where appropriate
- No → Consider ongoing carer support including helping them to stay well, living arrangements and respite care where appropriate → Consider referral to appropriate service as necessary e.g. Department of Work & Pensions for any welfare needs; DVLA for driving advice and support

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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 anti-dementia 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:
  – 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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- 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:

- 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_0SrE_VzIU

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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, http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/carers-assessment.aspx

Driving

- 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)

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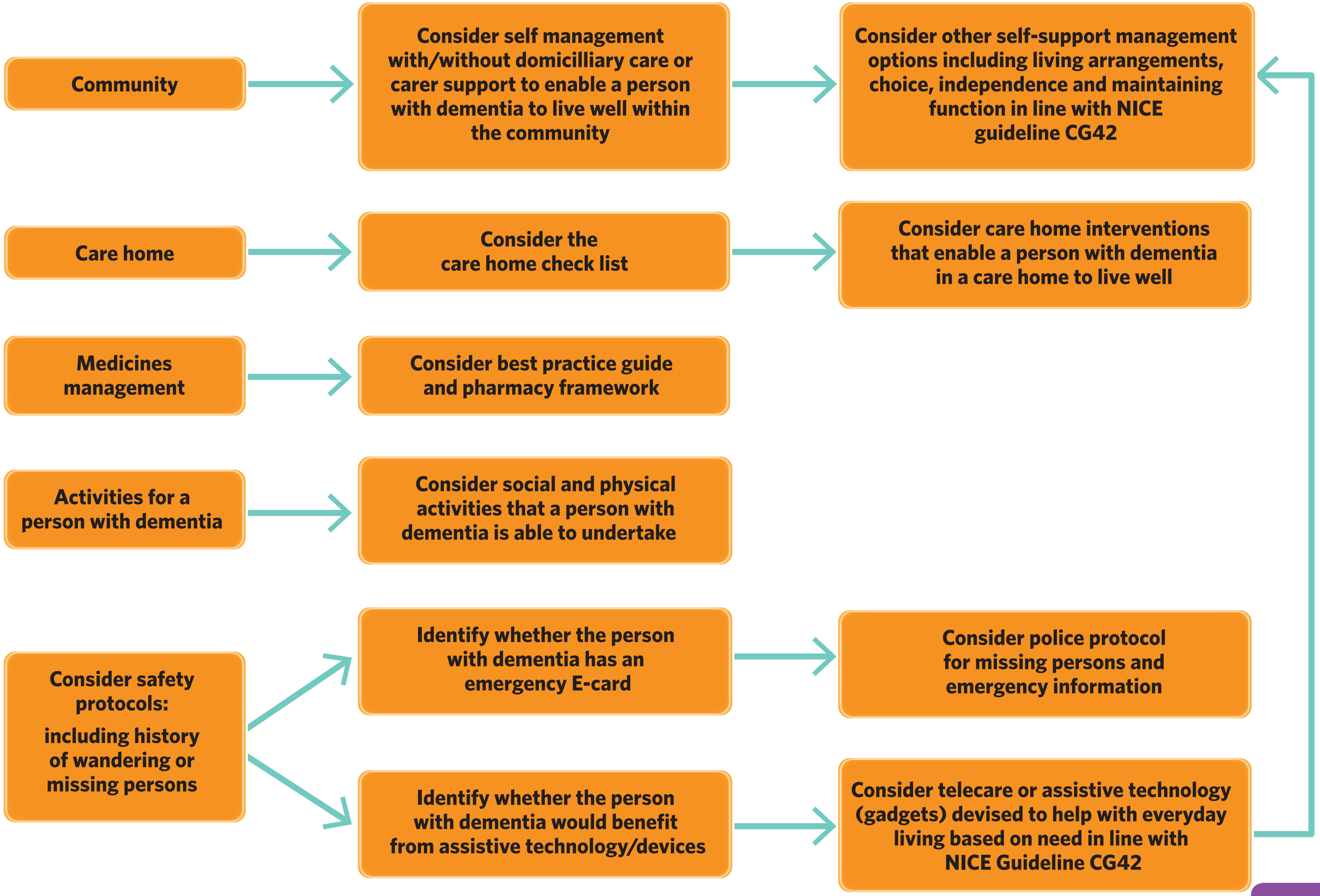

Community → Consider self management with/without domicilliary care or carer support to enable a person with dementia to live well within the community → Consider other self-support management options including living arrangements, choice, independence and maintaining function in line with NICE guideline CG42

Care home → Consider the care home check list → Consider care home interventions that enable a person with dementia in a care home to live well

Medicines management → Consider best practice guide and pharmacy framework

Activities for a person with dementia → Consider social and physical activities that a person with dementia is able to undertake

Consider safety protocols: including history of wandering or missing persons
- → Identify whether the person with dementia has an emergency E-card → Consider police protocol for missing persons and emergency information
- → Identify whether the person with dementia would benefit from assistive technology/devices → Consider telecare or assistive technology (gadgets) devised to help with everyday living based on need in line with NICE Guideline CG42 → Consider other self-support management options including living arrangements, choice, independence and maintaining function in line with NICE guideline CG42

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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
  - 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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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

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- 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

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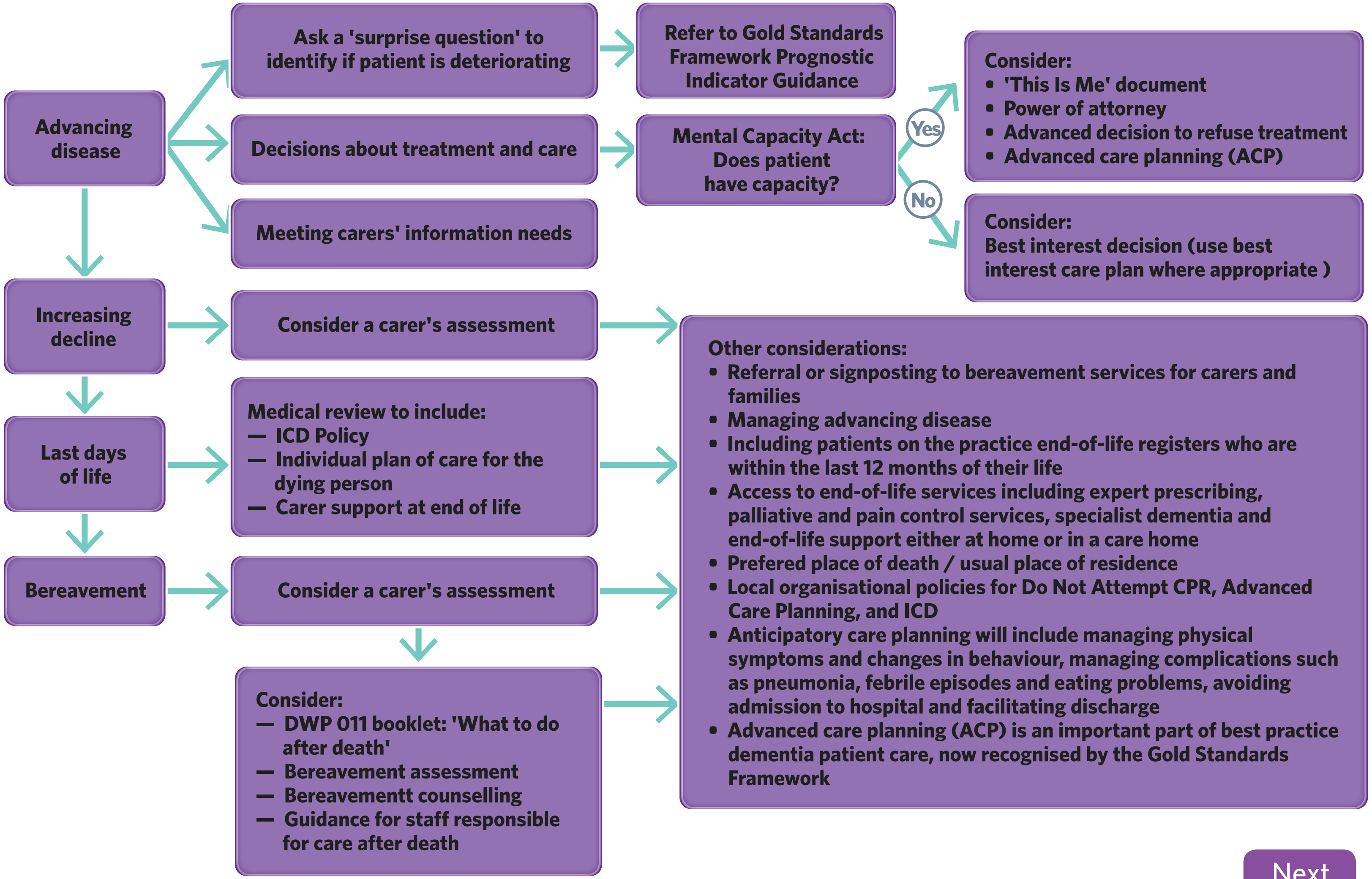
5 DYING WELL & BEREAVEMENT (1 of 3)

☒ Close



Advancing disease

- Ask a 'surprise question' to identify if patient is deteriorating → Refer to Gold Standards Framework Prognostic Indicator Guidance
- Decisions about treatment and care → Mental Capacity Act: Does patient have capacity?
  - Yes → Consider:
    - 'This Is Me' document
    - Power of attorney
    - Advanced decision to refuse treatment
    - Advanced care planning (ACP)
  - No → Consider: Best interest decision (use best interest care plan where appropriate)
- Meeting carers' information needs

Increasing decline → Consider a carer's assessment

Last days of life → Medical review to include:
— ICD Policy
— Individual plan of care for the dying person
— Carer support at end of life

Bereavement → Consider a carer's assessment → Consider:
— DWP 011 booklet: 'What to do after death'
— Bereavement assessment
— Bereavementt counselling
— Guidance for staff responsible for care after death

Other considerations:
- Referral or signposting to bereavement services for carers and families
- Managing advancing disease
- Including patients on the practice end-of-life registers who are within the last 12 months of their life
- Access to end-of-life services including expert prescribing, palliative and pain control services, specialist dementia and end-of-life support either at home or in a care home
- Prefered place of death / usual place of residence
- Local organisational policies for Do Not Attempt CPR, Advanced Care Planning, and ICD
- Anticipatory care planning will include managing physical symptoms and changes in behaviour, managing complications such as pneumonia, febrile episodes and eating problems, avoiding admission to hospital and facilitating discharge
- Advanced care planning (ACP) is an important part of best practice dementia patient care, now recognised by the Gold Standards Framework

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5 DYING WELL & BEREAVEMENT (2 of 3)

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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

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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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SYMPTOMS THAT SIGNIFY ONSET OF DEMENTIA (1 OF 7)

☒ Close

Memory loss

- Memory loss that disrupts daily life
- Problems with remembering recent events or conversations
- Forgetting appointments
- Constantly misplacing things, or forgetting things like leaving the cooker on
- Difficulty remembering names of people or everyday things
- Repeating things without realising
- Other people starting to notice and comment on forgetfulness

Mental functioning

- Difficulty completing familiar tasks at home, at work or at leisure
- New problems with words in speaking or writing
- Increasing difficulties with activities that need organisation and planning
- Difficulty with numbers and/or handling money in shops
- Finding it hard to follow the thread of conversations or programmes on TV
- Finding it hard to do tasks that need concentration, such as following recipes or instructions
- Problems finding the right words.
- Problems with sleeping and restlessness at night often occur.

Confusion

- Confusion with time or place
- Becoming confused in unfamiliar environments
- Getting lost easily, even in familiar routes
- Feeling disorientated at home, such as repeatedly going into a room and not sure why
- Poor judgement in making decisions, for example managing finances

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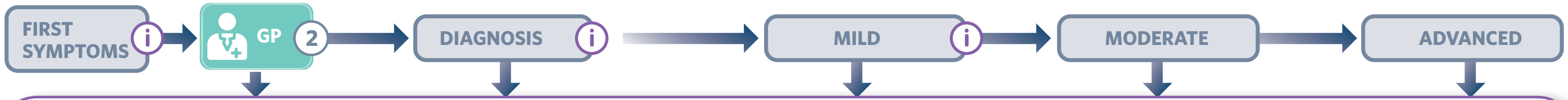

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i1 SYMPTOMS THAT SIGNIFY ONSET OF DEMENTIA (2 OF 7)

Behaviour

- Out of character behaviour, such as aggression or causing embarrassment in social situations
- Unusual behaviour, such as putting on clothes over pyjamas or putting things in unusual places
- Changes in sleep or appetite patterns
- Changes to level of care in personal grooming, laundry or house cleaning
- People may become increasingly unsteady on their feet and fall more often.
- People gradually require more help with daily activities like dressing, toileting and eating

Personality

- Withdrawal from work or social activities
- Changes in personality, for example used to be shy and quiet, but increasingly loud and boisterous
- Changes in mood, for example feeling anxious, depressed or angry
- Easily upset when out of comfort zone

NHS England Dementia diagnosis and management
(link: https://www.england.nhs.uk/wp-content/uploads/2015/01/dementia-diag-mng-ab-pt.pdf)

CLINICAL FEATURES OF A DEMENTIA SYNDROME

Dementia is a progressive loss of more than one area of cognitive function and is not considered part of normal aging although age is the biggest risk factor for the condition. It is an acquired and chronic state without impairment of consciousness which distinguishes it from learning disabilities and delirium. The signs and symptoms of a dementia syndrome should not be better explained by another process for example another psychiatric condition (depression, psychosis), physical illness or side effects of medication.

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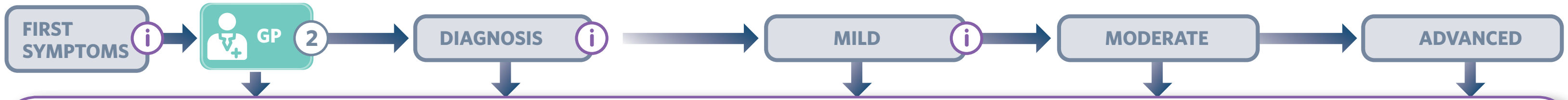

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CLINICAL FEATURES OF A DEMENTIA SYNDROME (3 OF 7)

☒ Close

Dementia can be considered as a clinical syndrome with three manifestations

- Neuropsychological, for example
  - Agnosia – memory loss
  - Apraxia – the inability to carry out tasks despite intact sensory and motor systems
  - Agnosia – inability to recognise things
  - Aphasia – difficulty understanding language and using language to express oneself
  - Executive symptoms – planning and organisation, reasoning, judgment

- Activities of Daily Living (ADLs)
  - Changes in cognitive function are often small to start with, but for someone with dementia they have become severe enough to affect their daily social and occupational functioning

- Neuropsychiatric
- Also known as Behavioural and Psychological symptoms of Dementia (BPSD)
- This includes wandering, agitation, aggression, depression, anxiety, psychosis
  - More likely to occur as dementia progresses
  - Often the reason for referral to secondary mental health services and admission

Diagnosing dementia is a two-stage process:

1. First one must decide if there is evidence of a dementia syndrome. Underlying medical and other psychiatric conditions must be ruled out by taking a history, including an informant history where possible, a physical examination and blood tests.
2. From the history and mental state examination it may be possible to identify the likely aetiology of the dementia. Additional investigations may be required for example imaging, detailed and detailed neuropsychological assessment, before the aetiology can be more accurately identified.

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i1 **CLINICAL FEATURES OF A DEMENTIA SYNDROME (4 OF 7)**

☒ Close

DEMENTIA SUBTYPES

Mild Cognitive Impairment (MCI)

- There must be objective evidence of cognitive impairment which is not normal for age
- No or very little impact on daily activities
- No or very little progression over time
- Over three years, approximately one third of patients with MCI spontaneously improve (suggesting that their symptoms were caused by depression, anxiety or a self-limiting physical illness), one third stay the same, and one third progress to dementia
- Cognitive enhancing medication is not routinely recommended

Alzheimer's Disease Insidious onset of symptoms with a gradual progression over time

- Early symptoms include difficulty with
- remembering new information ('poor short term' memory)
- recalling names of people and places ('word finding difficulties')
- planning and organisation
- disorientation to time and place
- emotional changes

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i1 **CLINICAL FEATURES OF A DEMENTIA SYNDROME (5 OF 7)** ☒ **Close**

DEMENTIA SUBTYPES

Vascular Dementia

- Presence of vascular risk factors
- There may be a family history of cerebrovascular disease
- Often past history of TIAs and Stroke
- Sudden onset, step-wise presentation – sometimes noticeable after a ‘funny do’, an episode of illness, or an operation
- Sometimes the steps can be so small the decline appears to be gradual
- Can remain static for long periods of time
- Cognitive problems evident within 3 months of a cerebrovascular event

Mixed Alzheimer’s/Vascular Dementia

- No clear distinction between AD and vascular dementia
- Combination of features

Dementia in Parkinson’s Disease

- Parkinson’s Disease is present for at least 12 months before the onset of cognitive decline
- One in six patients with Parkinson’s Disease develop an associated dementia which tends to become evident around 5-8 years following the diagnosis of PD

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i1 **CLINICAL FEATURES OF A DEMENTIA SYNDROME (6 OF 7)**

☒ Close

DEMENTIA SUBTYPES

Lewy Body Dementia (LBD)

- The onset of cognitive decline and Parkinsonian symptoms occurs within less than 12 months of each other.
- Memory may be well preserved at first but decline becomes evident with time
- The core features of LBD are
  - Fluctuating cognition with noticeable variations in attention and alertness
  - Recurrent, typically well-formed, visual hallucinations
- Spontaneous signs and symptoms of Parkinson's Disease
- Additional features include
  - Arousal at night and REM sleep disorder
  - Severe sensitivity to neuroleptic (antipsychotic) medication
  - Falls
  - Autonomic dysfunction e.g. urinary incontinence, orthostatic hypotension
  - Depression
  - Delusions

Frontotemporal Dementia (FTD)

- Sometimes called Pick's Disease although strictly speaking Pick's Disease is a rarer and neuropathologically specific sub type of FTD
- Often presents in a younger age group
- Insidious onset with a gradual and slow decline
- Three types: Behavioural Variant FTD
  Primary Progressive Aphasia
  Semantic dementia which are language variants of FTD

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i1 **CLINICAL FEATURES OF A DEMENTIA SYNDROME (7 OF 7)**

☒ Close

DEMENTIA SUBTYPES

Frontotemporal Dementia (FTD)

- Semantic dementia affects ones understanding of the meaning of words and facts hence the name semantic dementia. Speech is fluent but impoverished
- In Primary Progressive Aphasia the meaning of language is preserved but speech becomes non-fluent
- In the language variants other higher cortical functions tend to be well preserved in the early stages

Young onset dementia

Refers to those with onset of dementia before the age of 65 years.

Learning Disabilities

- Individuals with learning disability (LD) are at higher risk of developing dementia
- Association between Down's syndrome and Alzheimer's disease is well recognised
- Requires specialist assessment

References

https://www.england.nhs.uk/wp-content/uploads/2014/09/dementia-revealed-toolkit.pdf
https://www.alzheimers.org.uk
Bart Sheehan, Salman Karim, Alistair Burns, Old Age Psychiatry, Oxford Specialist Handbooks in Psychiatry, Oxford University Press, 2009

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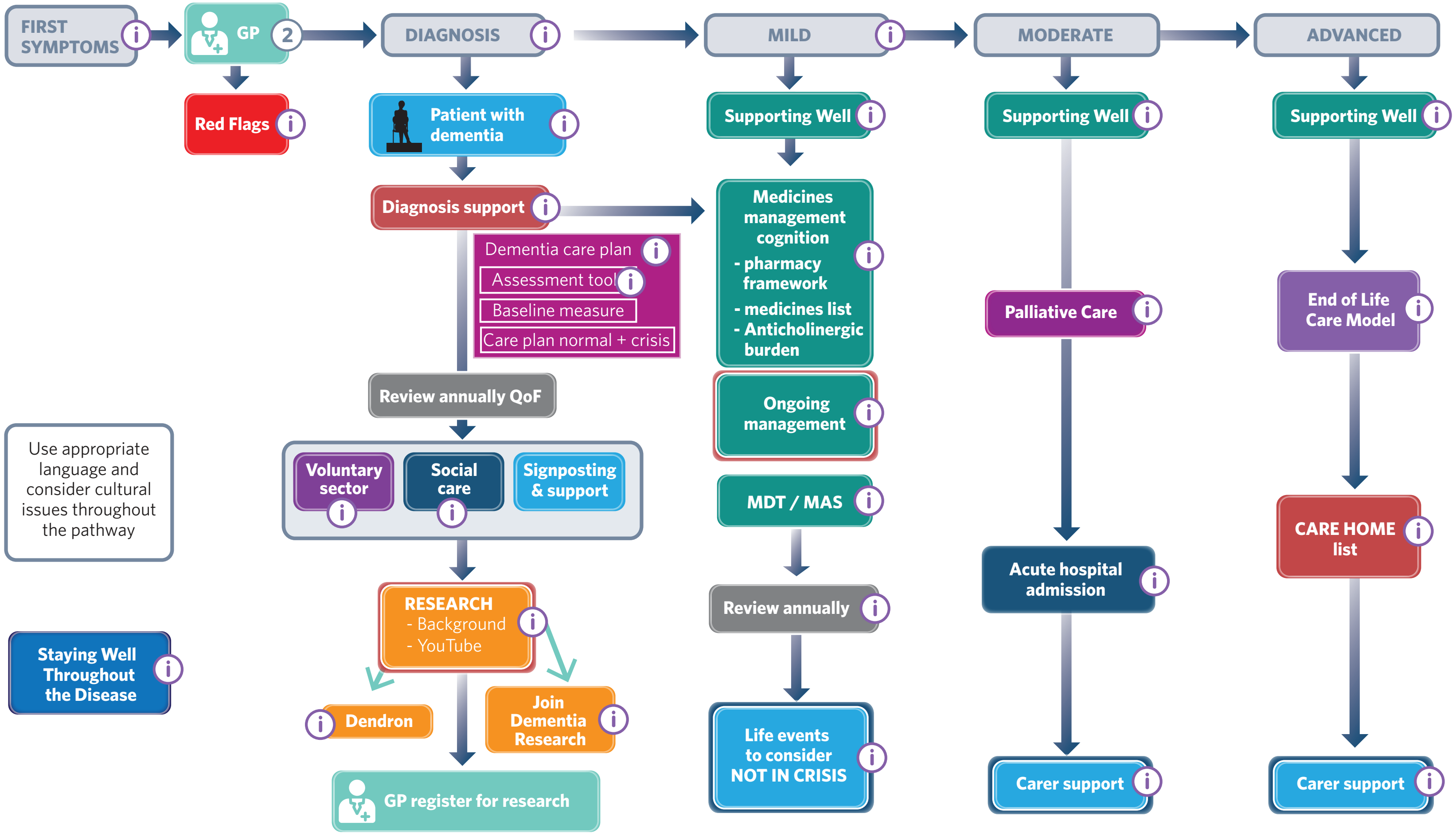

FIRST SYMPTOMS → GP → DIAGNOSIS → MILD → MODERATE → ADVANCED

GP
- Red Flags

DIAGNOSIS
- Patient with dementia
- Diagnosis support
  - Dementia care plan
  - Assessment tool
  - Baseline measure
  - Care plan normal + crisis
- Review annually QoF
- Voluntary sector | Social care | Signposting & support
- RESEARCH
  - Background
  - YouTube
- Dendron
- Join Dementia Research
- GP register for research

MILD
- Supporting Well
- Medicines management cognition
  - pharmacy framework
  - medicines list
  - Anticholinergic burden
- Ongoing management
- MDT / MAS
- Review annually
- Life events to consider NOT IN CRISIS

MODERATE
- Supporting Well
- Palliative Care
- Acute hospital admission
- Carer support

ADVANCED
- Supporting Well
- End of Life Care Model
- CARE HOME list
- Carer support

Use appropriate language and consider cultural issues throughout the pathway

Staying Well Throughout the Disease

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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

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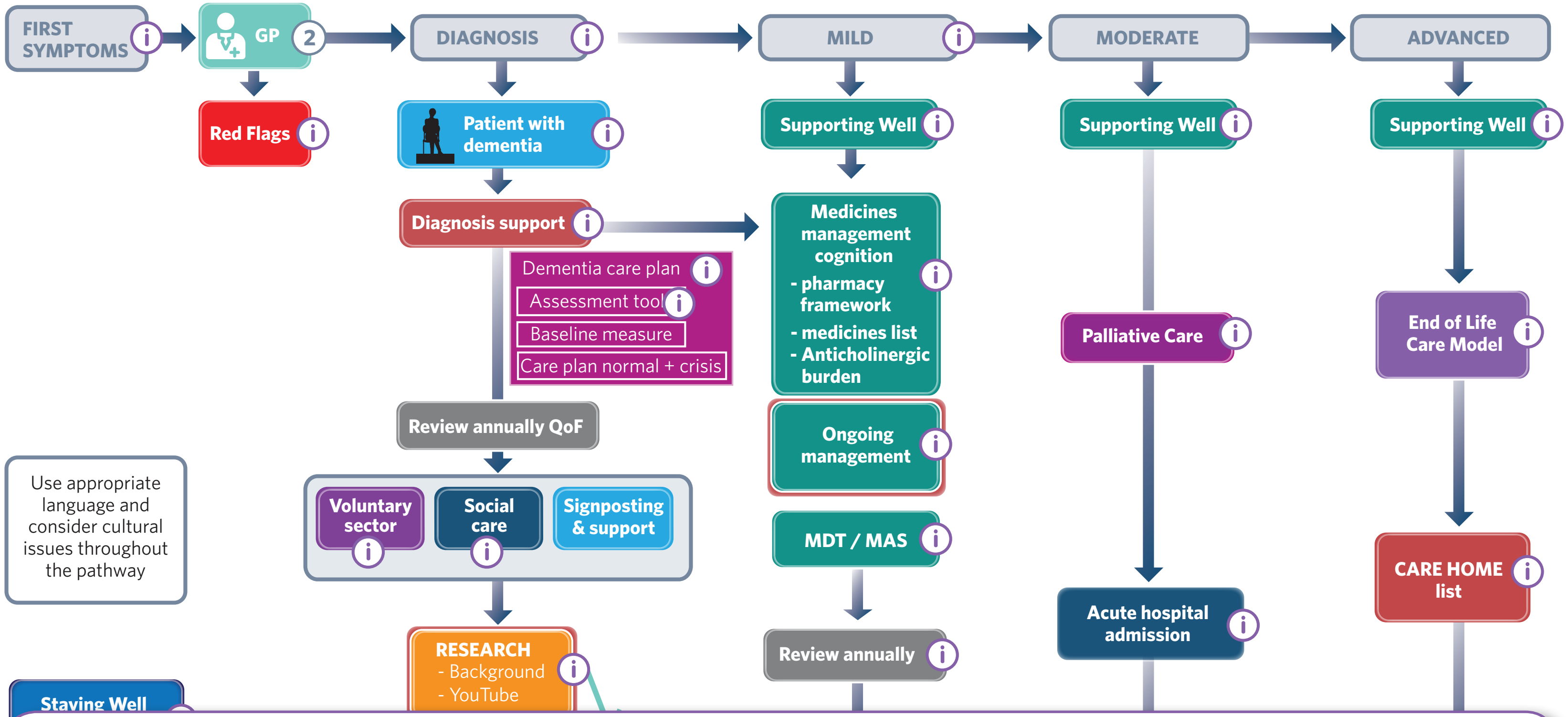

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RED FLAGS FOR GPS SUSPECTING DEMENTIA

First symptoms and red flags that indicate dementia include:

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Dementia with Lewy bodies	Normal pressure hydrocephalus	Cortical-basal degeneration
Early depression	Multiple falls	Early apraxia
Visual hallucinations	Gait change	Unilateral symptoms
Facial expression	Incontinence	Alien limb
Autonomic dysfunction		

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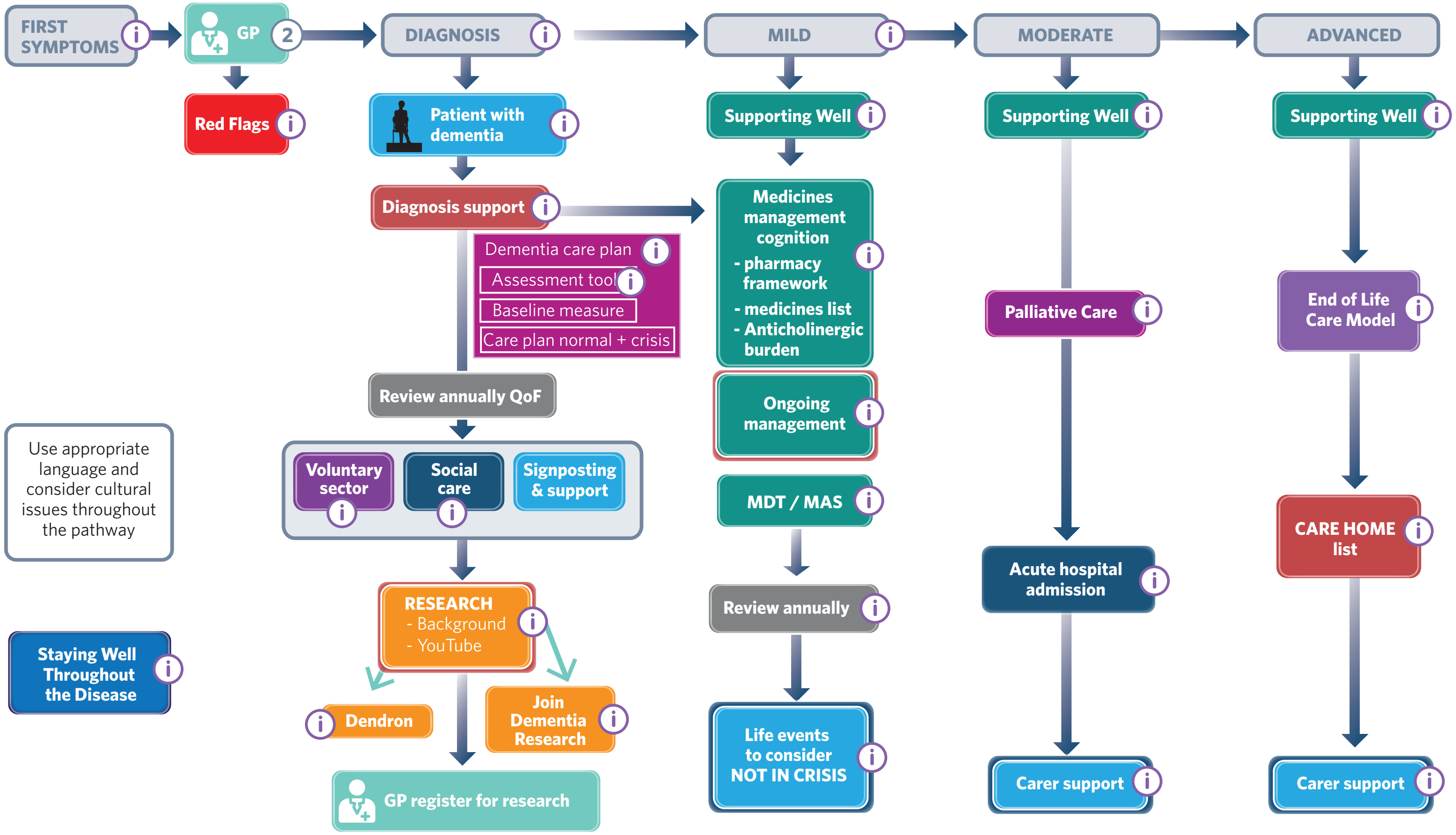

i4 **PATIENT WITH DEMENTIA**

Baseline “Normal assessment / Care plan - Normal patient details / Crisis support / Fears patient may have

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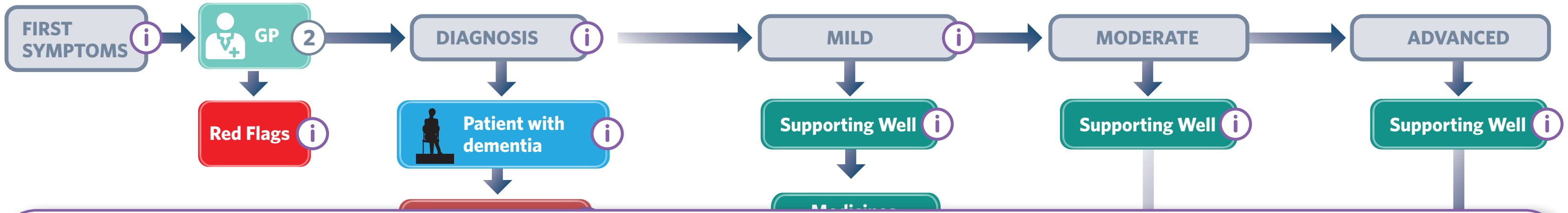

i5 SUPPORT AT DIAGNOSIS

☒ Close

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
- Risk factors, prevention and early identification
- Diagnosis and assessment
- Interventions for cognitive and non-cognitive symptoms, and comorbid emotional disorders
- Palliative care
- Support and interventions for carers

Consider:

- Holistic and person centred care (Whole system approach)
- 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
  - Commissioner checklist for dementia
  - What to expect from good quality dementia services

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i6 **DEMENTIA CARE PLAN – Sample care plan**

Link: SURP care planning template presentation.pdf

☒ Close

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
- Information provision
- Future care planning

A review might include:

- Living with dementia
- Cognition and medication
- Physical health check
- Risks and behaviours
- Avoiding unplanned admissions
- End of life

At the end of the review the GP or clinician will print a patient-held care plan.

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

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ASSESSMENT TOOLS FOR DIAGNOSIS AND MONITORING IN DEMENTIA (1 OF 5)

☒ Close

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.

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ASSESSMENT TOOLS FOR DIAGNOSIS AND MONITORING IN DEMENTIA (2 OF 5)

☒ Close

Montreal Cognitive Assessment (MoCA)

One page 30 point test

Administered in 10 minutes

Tests several areas of memory including:

- 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

General Practitioner Assessment of Cognition (GP COG)

A brief screening test for cognitive impairment, taking less than 10 minutes, specifically designed for primary care. It consists of:

- 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.

Mini Addenbrooke's Cognitive Assessment (Mini ACE)

A brief cognitive screening tool for dementia.

It is a 30 point test and contains items assessing:

- Orientation
- Memory
- Language
- Visuospatial

The Mini-ACE is derived from the well recognised and validated Addenbrooke's Cognitive Examination which is widely used in secondary care.

Using the Mini –ACE therefore allows for comparison and monitoring from pre-existing ACE data. The Mini-ACE is brief and achievable in a primary care setting

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ASSESSMENT TOOLS FOR DIAGNOSIS AND MONITORING IN DEMENTIA (3 OF 5)

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General Practitioner Assessment of Cognition (GP COG)

- **What is the best dementia screening instrument for general practitioners to use? American Journal of Geriatric Psychiatry, 2006. 14(5): p. 391-400** Found the GPCOG was a well validated tool in the community population and GP samples. It was also easy to administer.
- **Brief screening tests for dementia.. Canadian Journal of Psychiatry - Revue Canadienne de Psychiatrie, 2002. 47(8): p. 723-33.**
- **Screening for dementia in primary care: a review of the use, efficacy and quality of measures. International Psychogeriatrics, 2008. 20(5): p. 911-26.**

www.alz.org/documents_custom/gpcog(english).pdf

Mini Addenbrooke's Cognitive Assessment

- **The Mini-Addenbrooke's Cognitive Examination: A New Assessment Tool for Dementia (Hsieh et al).** This compared the Mini-ACE with the MMSE in patients with dementia as well as controls. They included patients with behavioural variant frontotemporal dementia, primary progressive aphasia, Alzheimers dementia and corticobasilar dementia. They used 2 cut off scores (25 and 21). They found that a cut off of 25 had a high sensitivity and specificity, however a cut off of <21 was almost certainly from a patient with dementia. The Mini-ACE was more sensitive than the MMSE and less like to have ceiling effects.

https://lodestone.neura.edu.au/frontier/ace-iii/

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i7 ASSESSMENT TOOLS FOR DIAGNOSIS AND MONITORING IN DEMENTIA (4 OF 5)

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Montreal Cognitive Assessment

- **MoCA versus MMSE as screening tool for diagnosing cognitive impairment in a memory clinic setting – A.J.Lamer (Walton Neurology Centre, Liverpool, UK)**. The study found the MoCA was accebptable, quick and easy to use. Using a cut off of < 26/30, it was more sensitive to then MMSE with better diagnostic accuracy. However it was less specific than the MMSE.
- **Evaluating the MoCA and Mini Mental State Exam for Cognitive Impairment Post Stroke – Lauren Friedman (University of Western Ontario).** Found that the MoCA demonstrated slightly better diagnostic accuracy then the MMSE and was a more sensitive tool
- **Cross validation of MoCA in community dwelling older adults residing in Southeastern US (Luis CA, Keegan AP, Mullan M).** MoCA appears to have utility for early detection of mild cognitive impairment and Alzheimers dementia. With cut off of <26/30 it detected 97% of those with cognitive impairment but with a specificity of 35%. Using a lower cut off of 23 resulted in both excellent sensitivity and specificity (96% and 95% respectively).
- **MoCA: validation study for Vascular Dementia (Freitas S, Simões MR, Alves L, Vicente M, Santana I). F**ound MoCA a valid, sensitive, reliable and accurate screening tool for patients with vascular dementia. MMSE and MoCA in Parkinson's disease and dementia with Lewy bodies: a multicenter 1-year follow-up study (Biundo R et al). Retrospective cohort study measuring MMSE and MoCA at baseline and 1 year. Found both to be equal in measuring rate of cognitive decline.

www.mocatest.org/pdf_files/test/MoCA-Test-English_7_1.pdf

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i7

ASSESSMENT TOOLS FOR DIAGNOSIS AND MONITORING IN DEMENTIA (5 OF 5)

☒ Close

General Practitioner Assessment of Cognition (GP COG)

- **What is the best dementia screening instrument for general practitioners to use? American Journal of Geriatric Psychiatry, 2006. 14(5): p. 391-400** Found the GPCOG was a well validated tool in the community population and GP samples. It was also easy to administer.
- **Brief screening tests for dementia.. Canadian Journal of Psychiatry - Revue Canadienne de Psychiatrie, 2002. 47(8): p. 723-33.**
- **Screening for dementia in primary care: a review of the use, efficacy and quality of measures. International Psychogeriatrics, 2008. 20(5): p. 911-26.**

www.alz.org/documents_custom/gpcog(english).pdf

Mini Addenbrooke's Cognitive Assessment

- **The Mini-Addenbrooke's Cognitive Examination: A New Assessment Tool for Dementia (Hsieh et al).** This compared the Mini-ACE with the MMSE in patients with dementia as well as controls. They included patients with behavioural variant frontotemporal dementia, primary progressive aphasia, Alzheimers dementia and corticobasilar dementia. They used 2 cut off scores (25 and 21). They found that a cut off of 25 had a high sensitivity and specificity, however a cut off of <21 was almost certainly from a patient with dementia. The Mini-ACE was more sensitive than the MMSE and less like to have ceiling effects.

https://lodestone.neura.edu.au/frontier/ace-iii/

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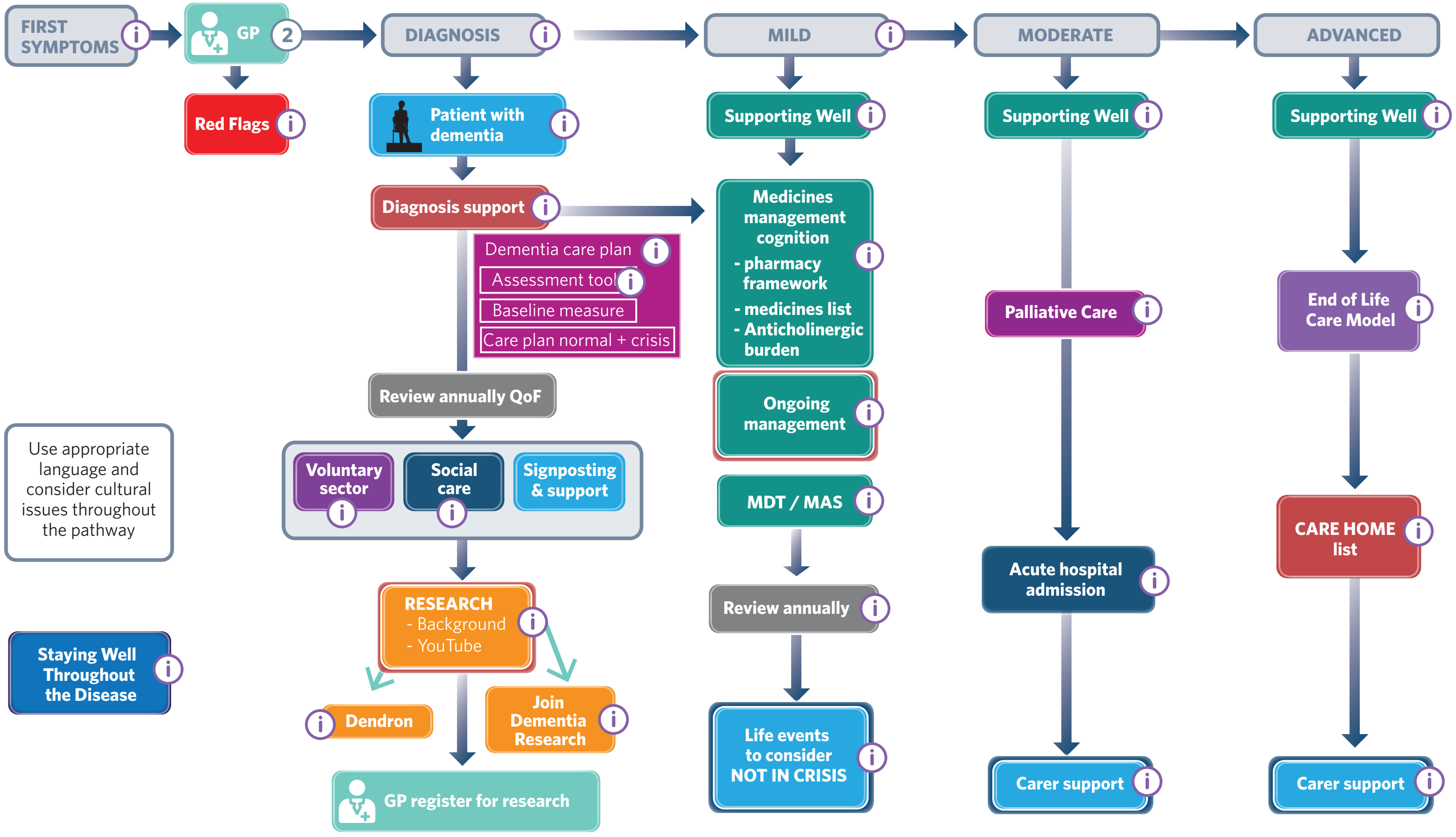

FIRST SYMPTOMS ⓘ → GP ② → DIAGNOSIS ⓘ → MILD ⓘ → MODERATE → ADVANCED

GP → Red Flags ⓘ

DIAGNOSIS → Patient with dementia ⓘ → Diagnosis support ⓘ → Medicines management cognition

- Dementia care plan ⓘ
- Assessment tool ⓘ
- Baseline measure
- Care plan normal + crisis

Review annually QoF

Voluntary sector ⓘ | Social care ⓘ | Signposting & support

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ⓘ Dendron

Join Dementia Research ⓘ

GP register for research

Use appropriate language and consider cultural issues throughout the pathway

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ADVANCED → Supporting Well ⓘ → End of Life Care Model ⓘ → CARE HOME list ⓘ → Carer support ⓘ

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i8 **VOLUNTARY SECTOR**

ⓘ Link: https://www.alzheimers.org.uk/

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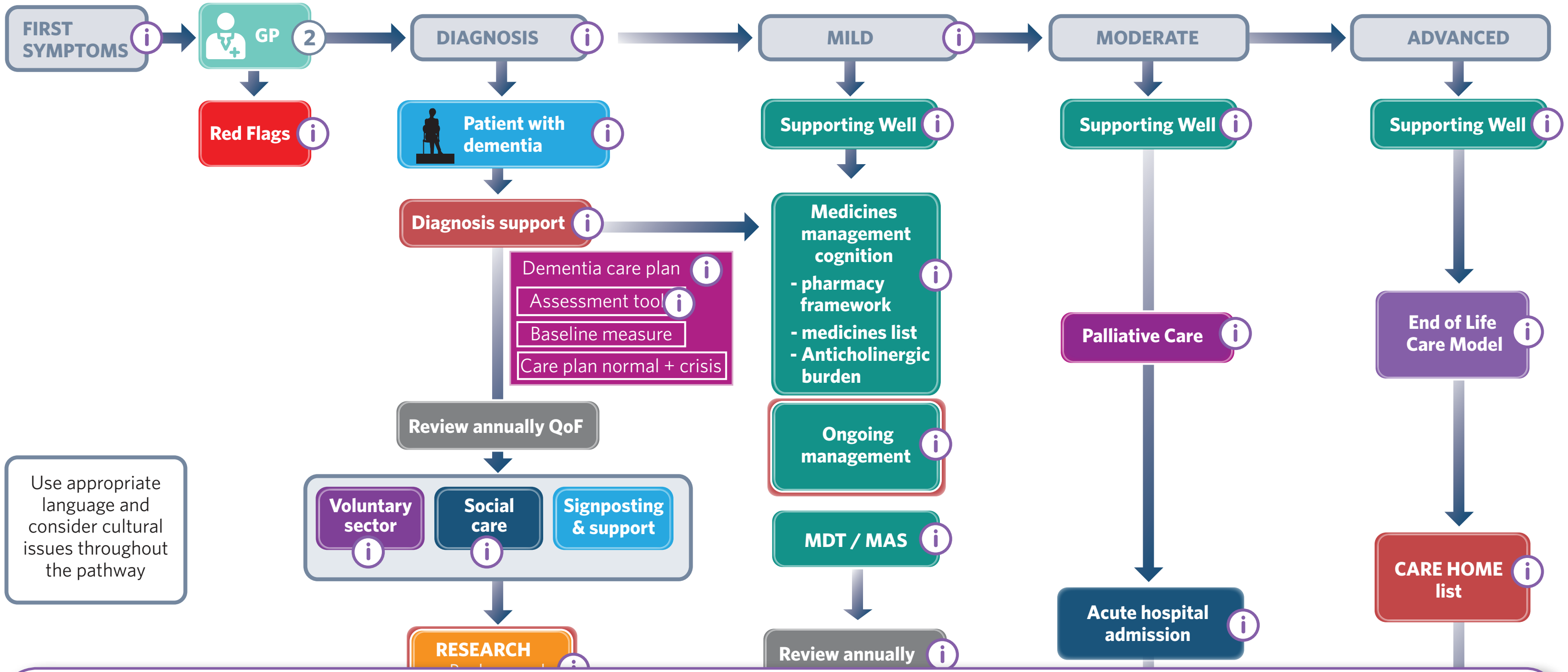

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i9 **SOCIAL CARE** ☒ Close

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)

SCIE Guide 47 - Personalisation: a rough guide (SCIE, 2012)

SCIE Guide 52 - GP services for older people: a guide for care home managers (SCIE, 2013)

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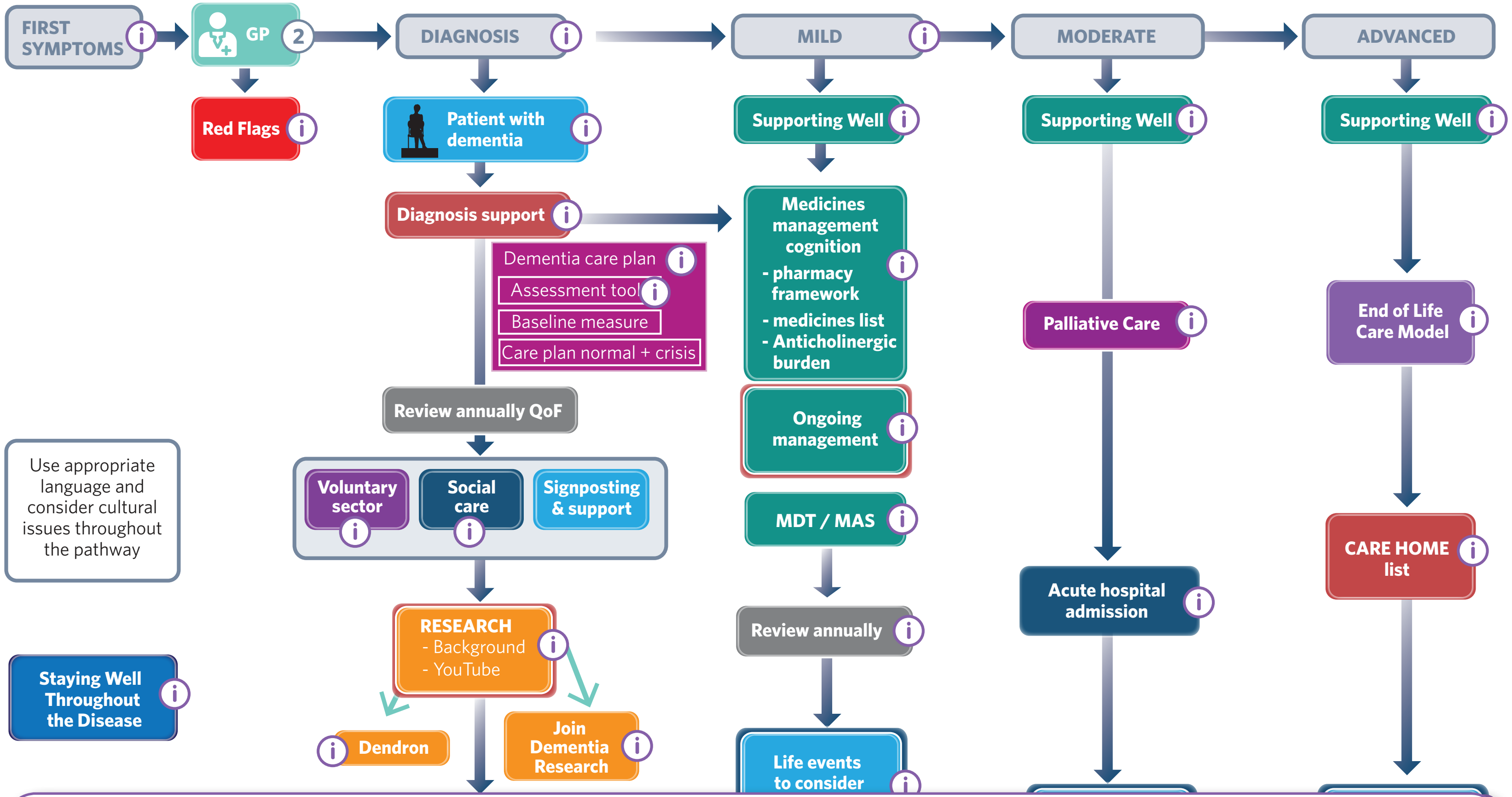

Use appropriate language and consider cultural issues throughout the pathway

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i10 RESEARCH

☒ Close

Link: Link: Dementia Research guidance GMLSC SCNs.pdf

Link: https://www.youtube.com/watch?v=BRbpXJ5WCLI

Link: https://www.joindementiaresearch.nihr.ac.uk/

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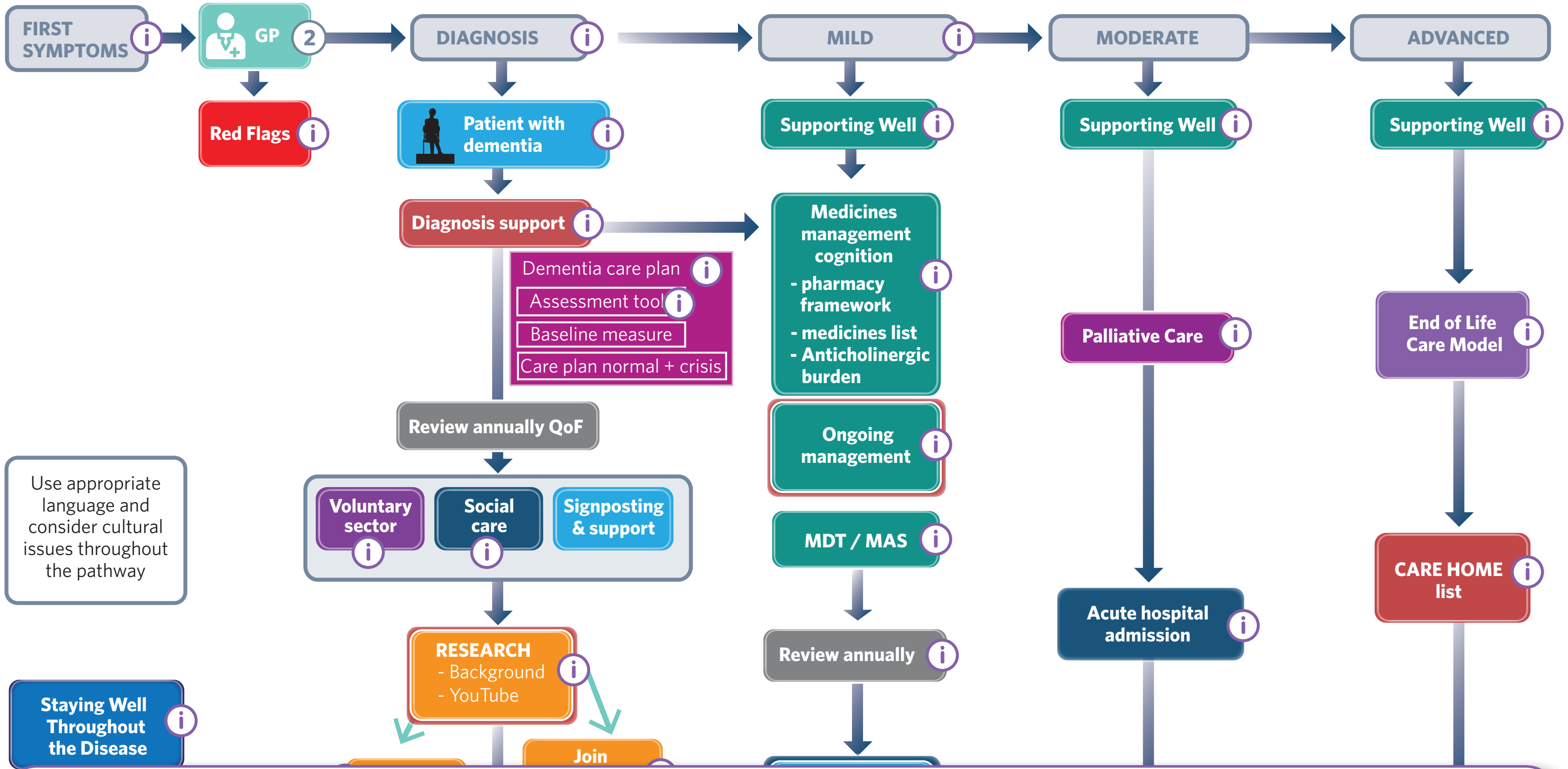

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i11 RESEARCH

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Dendron

Link: https://www.crn.nihr.ac.uk/dementia/about-dementia-research/research/

Join Dementia Research

Link: https://www.joindementiaresearch.nihr.ac.uk/

i12 MILD - MEDICINES MANAGEMENT TABLE (1 OF 3)

☒ Close

	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	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 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.			

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i12 MILD - MEDICINES MANAGEMENT TABLE (2 OF 3)

☒ Close

	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, COPD, cardiac conduction abnormalities, peptic ulcers, seizures.			Hx of seizures

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i12 ANTICHOLINERGIC BURDEN (ACB) (3 OF 3)

☒ Close

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).

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

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

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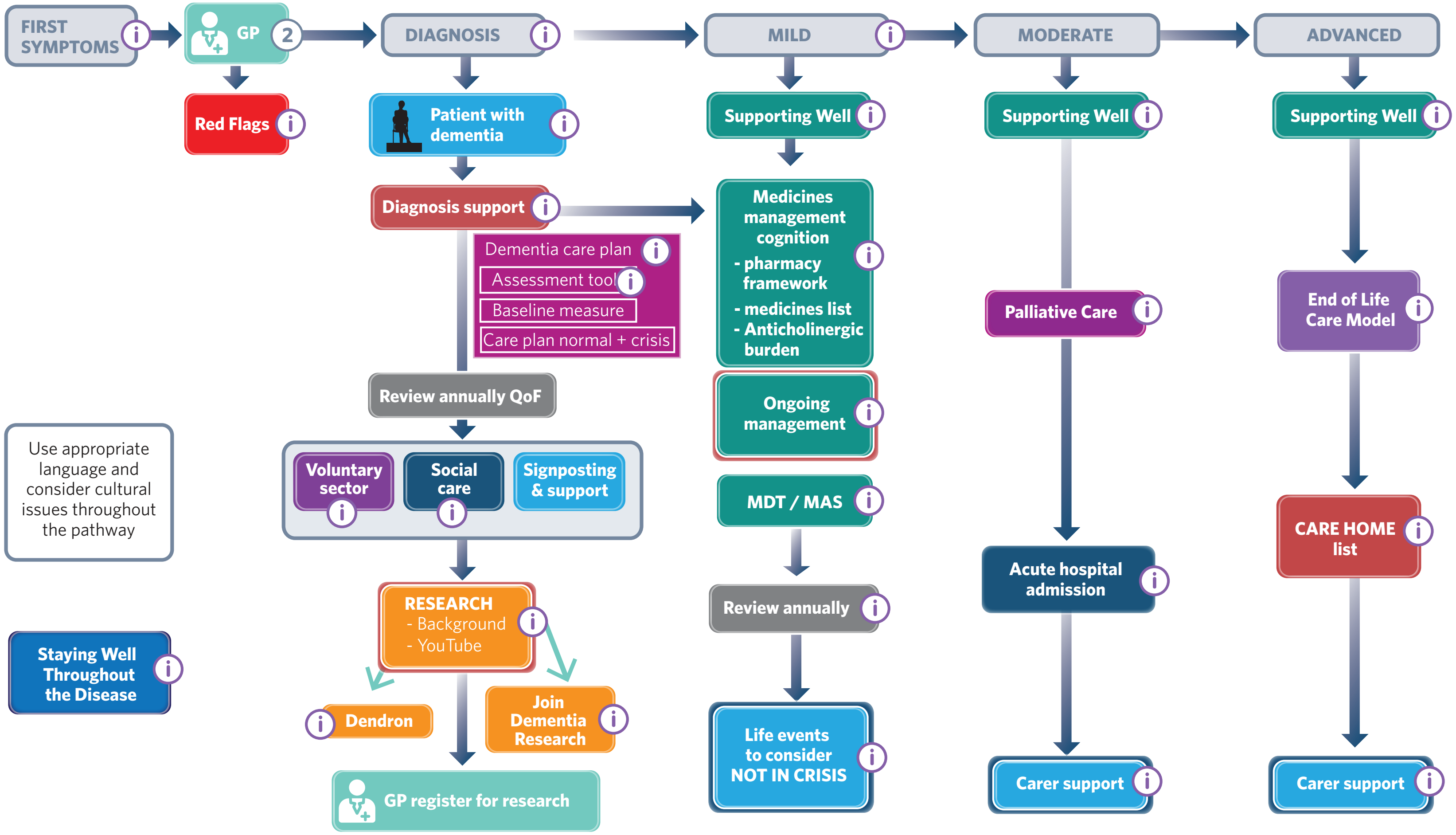

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Red Flags

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i13 **Ongoing Management**
Add in short summary of MDT OT Psychology

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Memory Assessment Services (MAS) (1 of 4)

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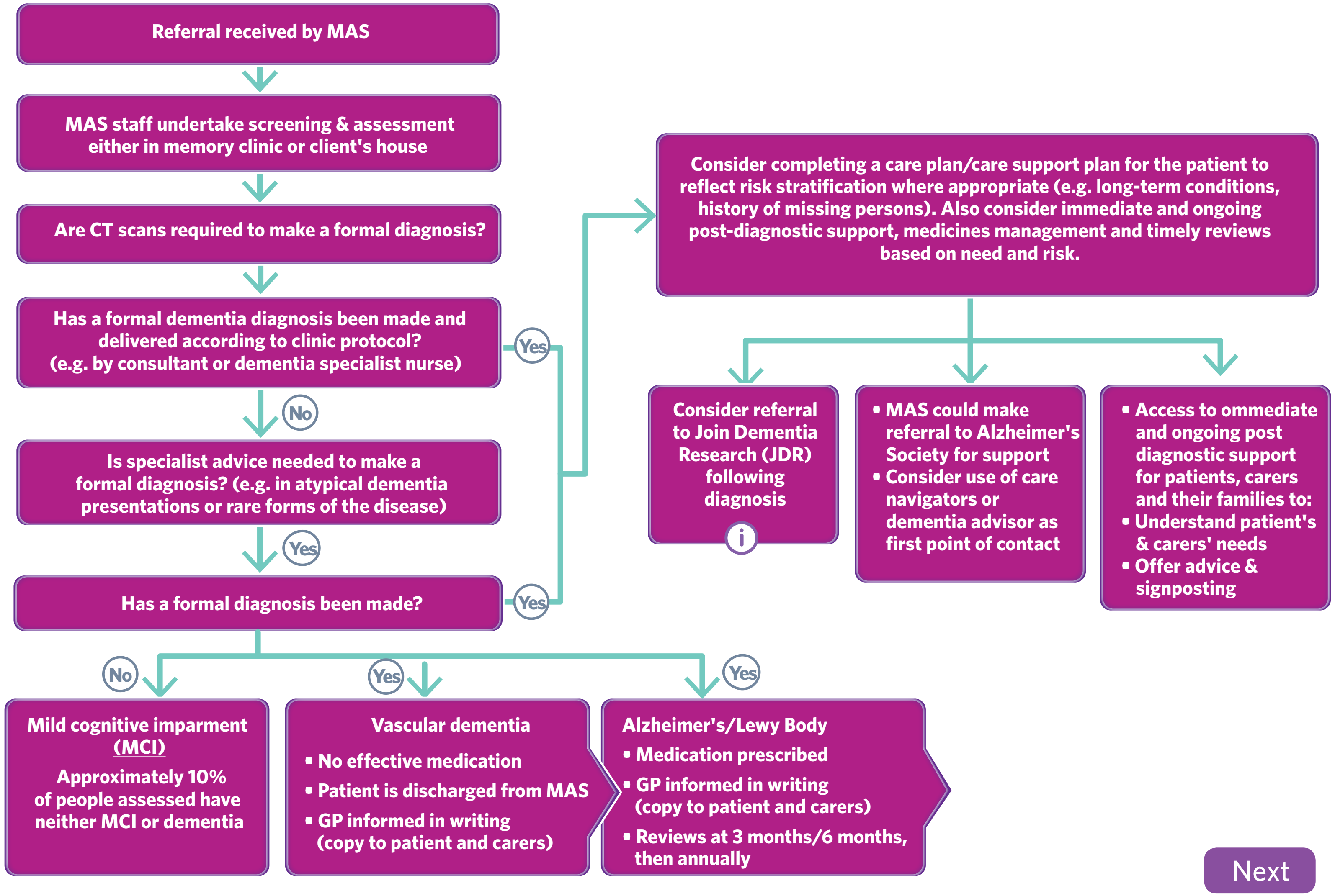

Referral received by MAS

MAS staff undertake screening & assessment either in memory clinic or client's house

Are CT scans required to make a formal diagnosis?

Has a formal dementia diagnosis been made and delivered according to clinic protocol? (e.g. by consultant or dementia specialist nurse)

No

Is specialist advice needed to make a formal diagnosis? (e.g. in atypical dementia presentations or rare forms of the disease)

Yes

Has a formal diagnosis been made?

Yes

Consider completing a care plan/care support plan for the patient to reflect risk stratification where appropriate (e.g. long-term conditions, history of missing persons). Also consider immediate and ongoing post-diagnostic support, medicines management and timely reviews based on need and risk.

Consider referral to Join Dementia Research (JDR) following diagnosis

- MAS could make referral to Alzheimer's Society for support
- Consider use of care navigators or dementia advisor as first point of contact

- Access to ommediate and ongoing post diagnostic support for patients, carers and their families to:
- Understand patient's & carers' needs
- Offer advice & signposting

No

Mild cognitive impartment (MCI)

Approximately 10% of people assessed have neither MCI or dementia

Yes

Vascular dementia

- No effective medication
- Patient is discharged from MAS
- GP informed in writing (copy to patient and carers)

Yes

Alzheimer's/Lewy Body

- Medication prescribed
- GP informed in writing (copy to patient and carers)
- Reviews at 3 months/6 months, then annually

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

☒ Close

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/

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i14 Service Specification for Memory Assessment Services (MAS) (3 of 4)

☒ Close

Mild Cognitive Impairment (MCI)

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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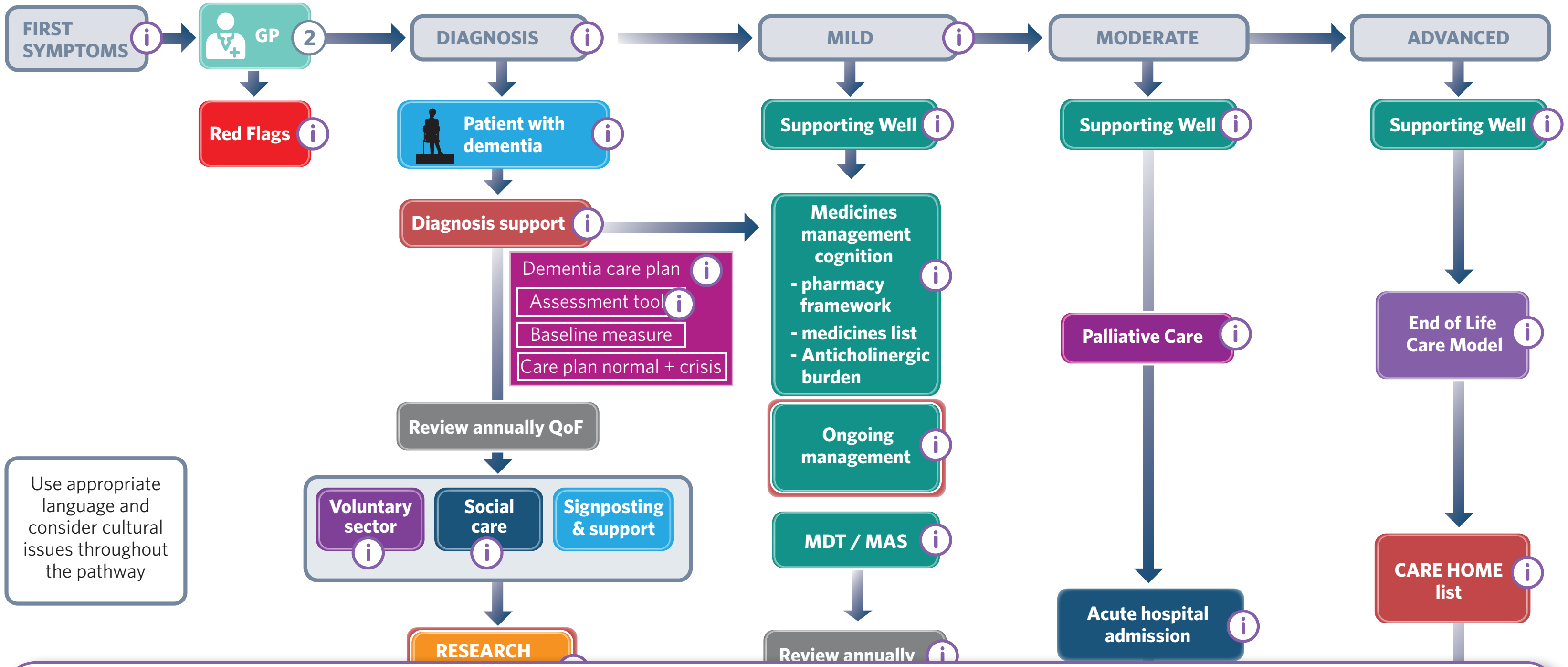

FIRST SYMPTOMS → GP → DIAGNOSIS → MILD → MODERATE → ADVANCED

Red Flags

Patient with dementia

Diagnosis support

Dementia care plan

Assessment tool

Baseline measure

Care plan normal + crisis

Review annually QoF

Voluntary sector

Social care

Signposting & support

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Use appropriate language and consider cultural issues throughout the pathway

Supporting Well

Medicines management cognition
- pharmacy framework
- medicines list
- Anticholinergic burden

Ongoing management

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Palliative Care

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

☒ Close

Links to other services

Suggestions from the MAS for GP referral to stroke clinic or vascular services

Annual Review

- 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)

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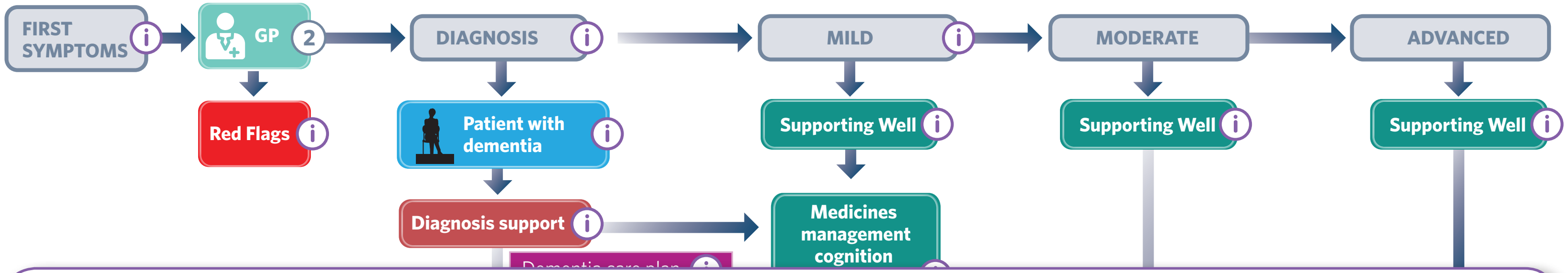

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i15 **Review annually** ☒ **Close**

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.

A review might include:

- Living with dementia
- Cognition and medication
- Physical health check
- Risks and behaviours
- Avoiding unplanned admissions
- End of life.

At the end of the review the GP or clinician will print off a patient held care plan (see example)
Link: SURP care planning template presentation.pdf

NHS Dementia Well pathway Framework Domains

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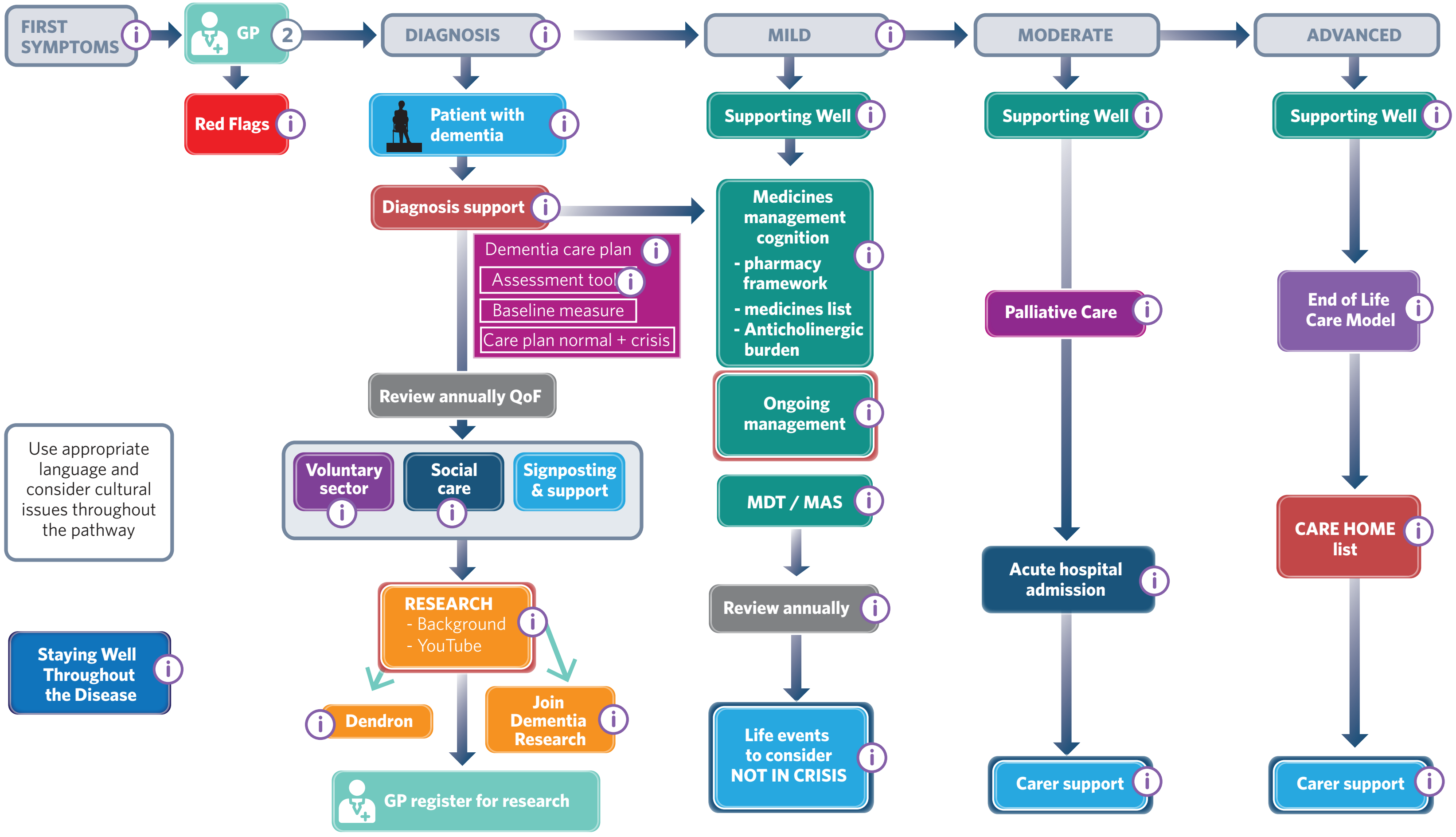

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i16 **Life Events to consider /NOT IN CRISIS**

Driving / Travel / moving care home /Legal POA

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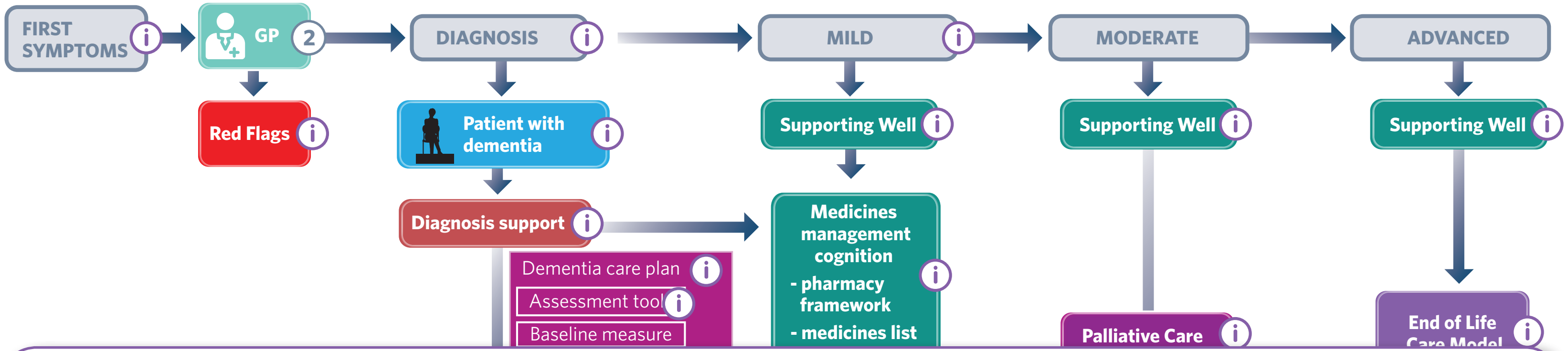

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Supporting Well
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i17 **SUPPORTING WELL**

☒ Close

Tips and best Practice for Supporting Well

- Effective Communication
- Advocacy and Empowerment
- Focus on capabilities not dependencies
- Use of new technologies and Telemedicine
- Training and Support for staff and Families
- Treatment advice out of hospital
- Effective Signposting
- Timely Reviews
- Telecare
- Housing
- Safety and Security
- Education and better understanding of the condition can help support better patient care by directing patients, their carers and families to the appropriate services
- Clear Roles and Responsibilities needed for appropriate signposting - consider the various tiers of training and health and social care groups where appropriate.

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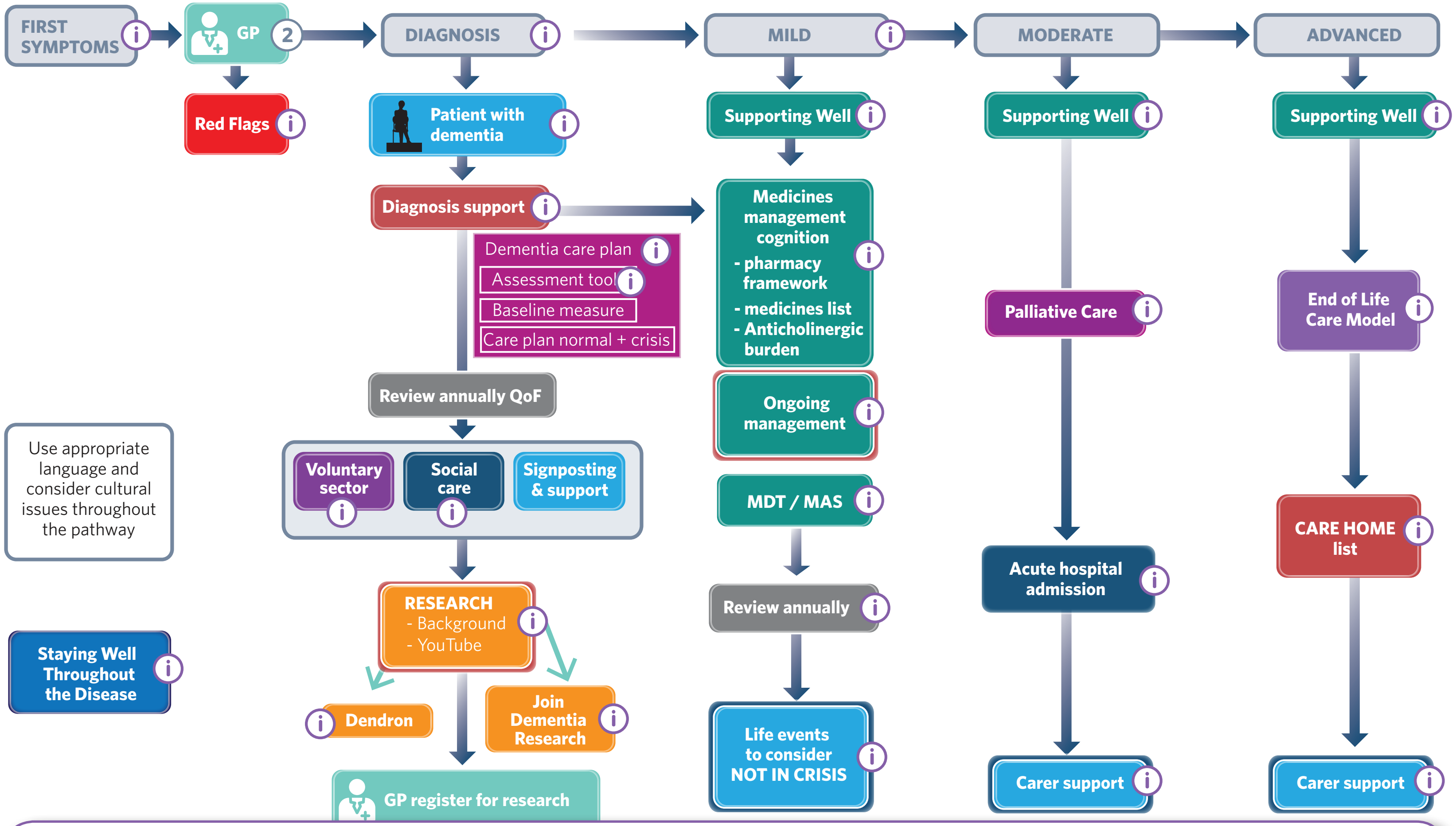

FIRST SYMPTOMS ⓘ → GP ② → DIAGNOSIS ⓘ → MILD ⓘ → MODERATE → ADVANCED

GP → Red Flags ⓘ

DIAGNOSIS → Patient with dementia ⓘ → Diagnosis support ⓘ

- Dementia care plan ⓘ
- Assessment tool ⓘ
- Baseline measure
- Care plan normal + crisis

Review annually QoF

Voluntary sector ⓘ | Social care ⓘ | Signposting & support

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- YouTube ⓘ

ⓘ Dendron

Join Dementia Research ⓘ

GP register for research

Use appropriate language and consider cultural issues throughout the pathway

Staying Well Throughout the Disease ⓘ

MILD → Supporting Well ⓘ → Medicines management cognition ⓘ
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- Anticholinergic burden

Ongoing management ⓘ

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ADVANCED → Supporting Well ⓘ → End of Life Care Model ⓘ → CARE HOME list ⓘ → Carer support ⓘ

i18 **PALLIATIVE CARE**

A guide to symptom management in palliative care:

Link: https://www.yorkhospitals.nhs.uk/document.php?o=2360

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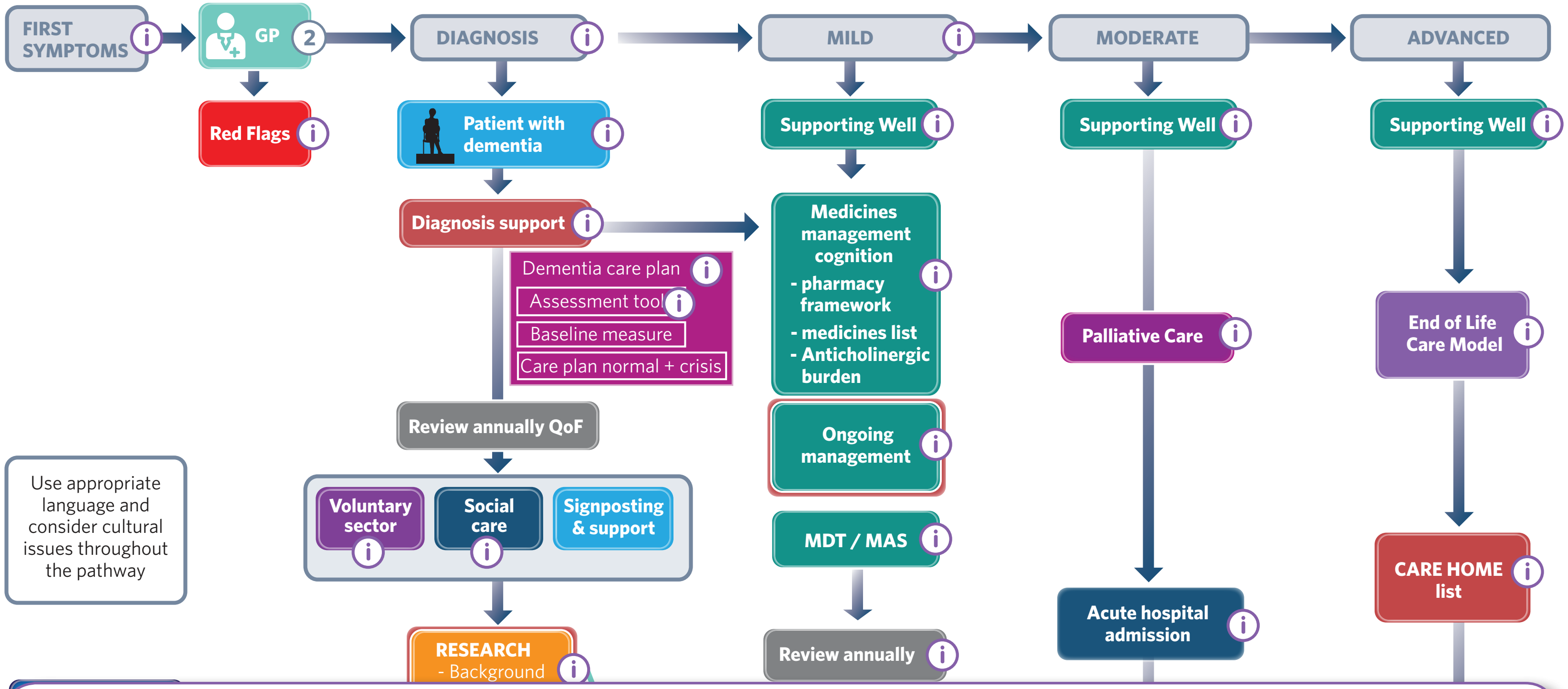

Use appropriate language and consider cultural issues throughout the pathway

NHS Dementia Well pathway Framework Domains

1. Preventing Well
2. Diagnosing Well
3. Supporting Well
4. Living Well
5. Dying Well

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i19 CRISIS - POLICE

☒ Close

Links:

Herbert protocol leaflet.pdf

Dementia guardian leaflet.pdf

Dementia leaflet.pdf

Link: Voluntary sector

The Herbert Protocol
Missing Person Information Form

Look Out For This Logo

DEMENTIA BUDDY

On Any Of These Devices

Guardian Angels

Tap Your NFC Enabled Phone To Get Them Home

IN CASE OF EMERGENCY CONTACT DETAILS

DEMENTIA

DON'T STALL, MAKE THE CALL

WHAT TO DO WHEN A PERSON WITH DEMENTIA GOES MISSING

CALL 101

POLICE

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FIRST SYMPTOMS ⓘ → GP ② → DIAGNOSIS ⓘ → MILD ⓘ → MODERATE → ADVANCED

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③ Supporting Well
④ Living Well
⑤ Dying Well

i20 CRISIS - AMBULANCE

☒ Close

Message in a bottle

‘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

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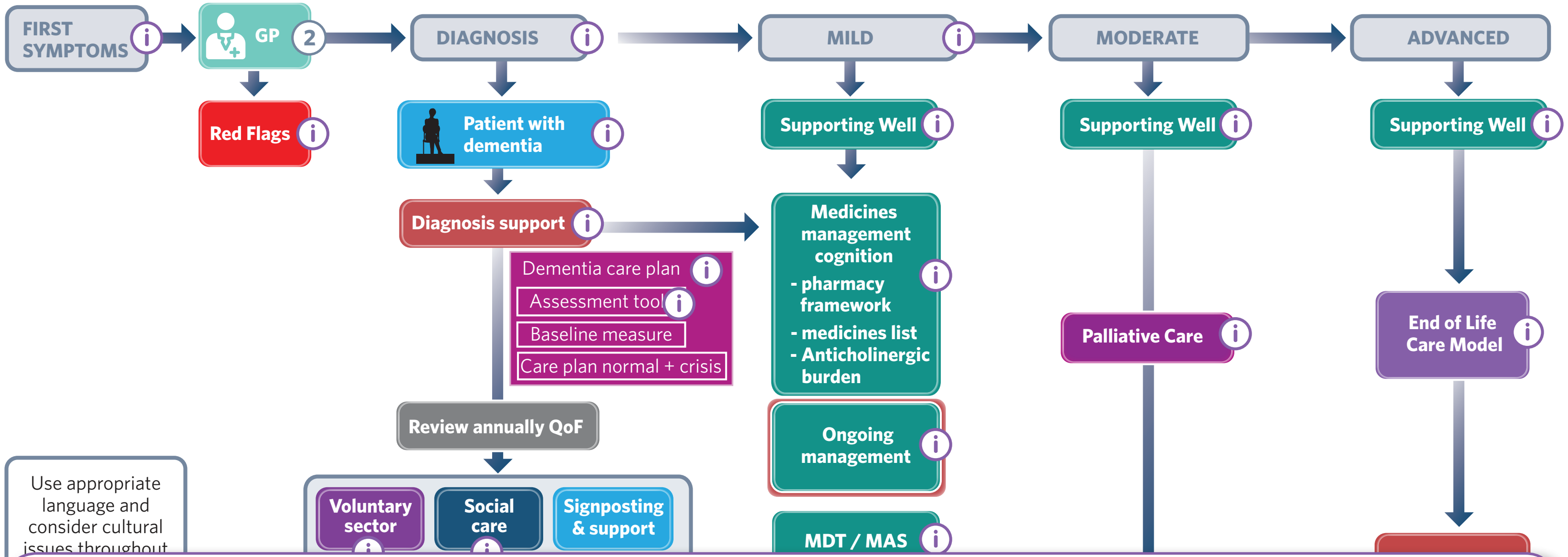

FIRST SYMPTOMS i → GP 2 → DIAGNOSIS i → MILD i → MODERATE → ADVANCED

Red Flags i

Patient with dementia i

Diagnosis support i

Dementia care plan i
Assessment tool i
Baseline measure
Care plan normal + crisis

Review annually QoF

Voluntary sector i
Social care i
Signposting & support

Use appropriate language and consider cultural issues throughout

Supporting Well i

Medicines management cognition i
- pharmacy framework
- medicines list
- Anticholinergic burden

Ongoing management i

MDT / MAS i

Supporting Well i

Palliative Care i

Supporting Well i

End of Life Care Model i

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i21 ACUTE HOSPITAL ADMISSION

☒ Close

Preventing avoidable emergency admissions to acute general hospitals

- Programmes to help prevent admissions include:
- Case management
- Crisis resolution teams
- Intermediate care
- Telehealth
- Team-based interventions in A&E
- Proactive management of long-term conditions
- Evidence around renewed slips, trips and falls initiatives, particularly targeted at older people with dementia is required

Link: http://www.yhpho.org.uk/resource/view.aspx?RID=207311

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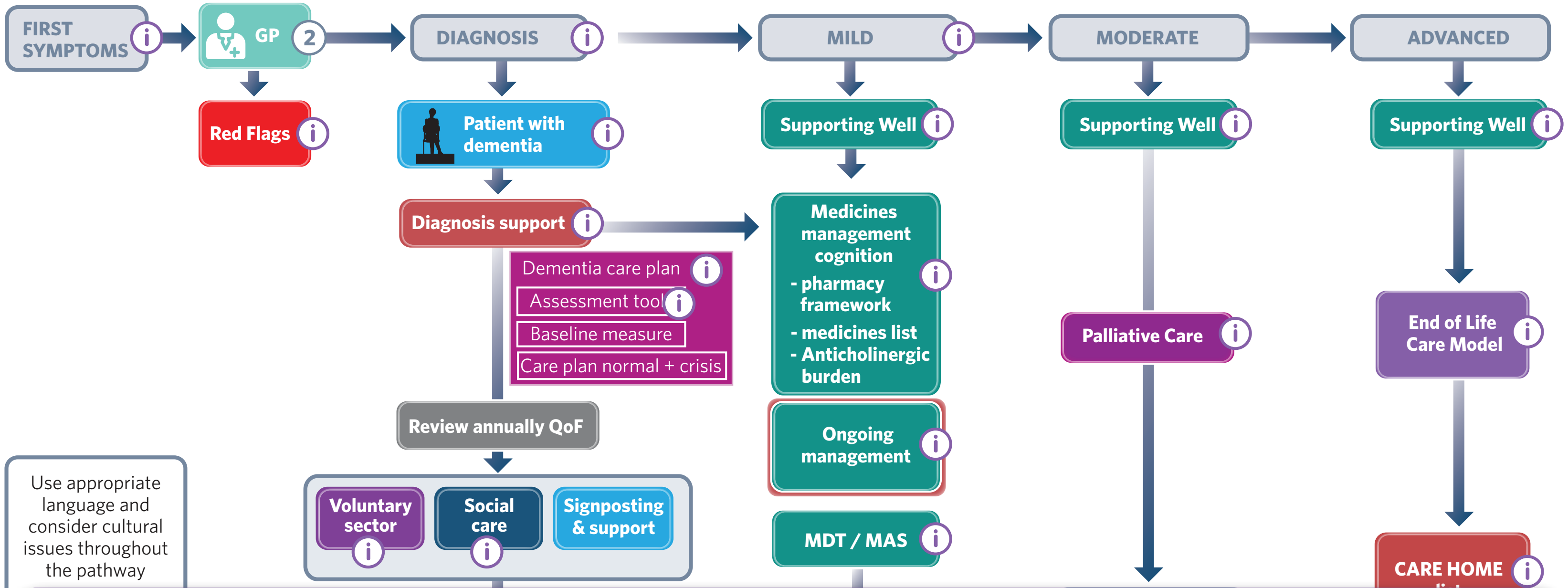

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i22 Carer Support

Carers:

- Have a legal right to an assessment of their needs
- 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 with regards to assessment and referral
- 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.
- Should also be able to self-refer for an assessment.

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

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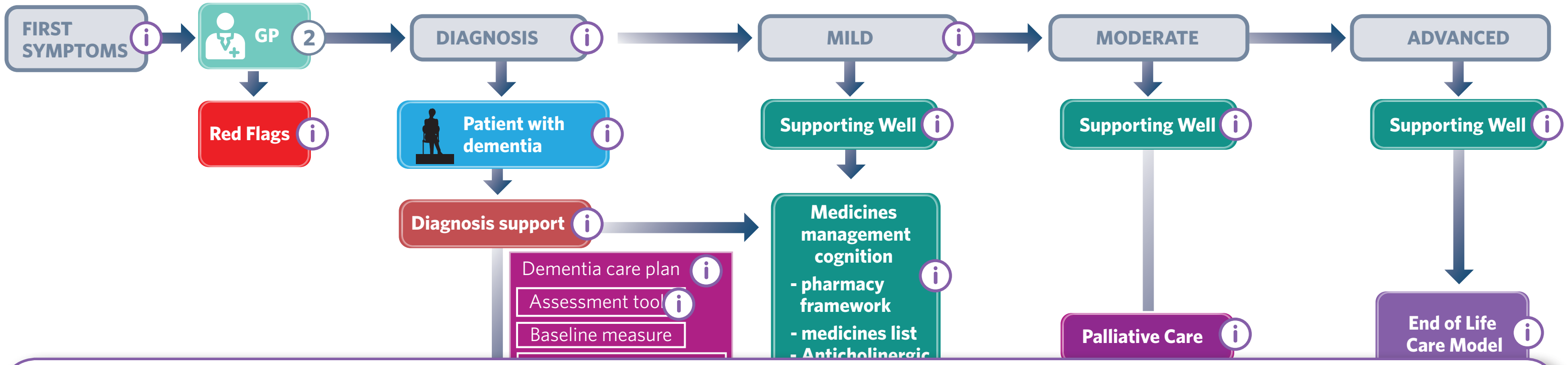

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i23 END OF LIFE CARE MODEL (1 of 3)

☒ Close

The model comprises five phases which identifies key elements of practice within each phase. The model supports the assessment and planning process for patients from the diagnosis of the life-limiting illness or those who may be frail.

For further details about good practice in palliative care visit:

National Council for Palliative Care, http://www.ncpc.org.uk
Health Education England, hee.nhs.uk
NHS England, www.england.nhs.uk

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i23 END OF LIFE CARE MODEL (2 of 3)

☒ Close

LAST YEAR OF LIFE Year/s	INCREASING DECLINE Months/Weeks	LAST DAYS OF LIFE Days	CARE AFTER DEATH 1 year/s
• 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

ADRT - Advance Decision to Refuse Treatment
DNACPR - Do Not Attempt Cardio Pulmonary Resuscitation
EPaCCS - Electronic Palliative Care Coordinating System
GP - General Practitioner
ICD - Implantable Cardioverter Defibrillator
NWAS - North West Ambulance Service
OOH - Out of Hours
PPC - Preferred Priorities of Care

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i23 **END OF LIFE CARE MODEL (3 of 3)**

☒ Close

LAST YEAR OF LIFE Year/s	INCREASING DECLINE Months/Weeks	LAST DAYS OF LIFE Days	CARE AFTER DEATH 1 year/s
• 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	• Ongoing communication with 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 and when necessary • ICD discussion and deactivation	• 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

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ADRT - Advance Decision to Refuse Treatment
DNACPR - Do Not Attempt Cardio Pulmonary Resuscitation
EPaCCS - Electronic Palliative Care Coordinating System
GP - General Practitioner
ICD - Implantable Cardioverter Defibrillator
NWAS - North West Ambulance Service
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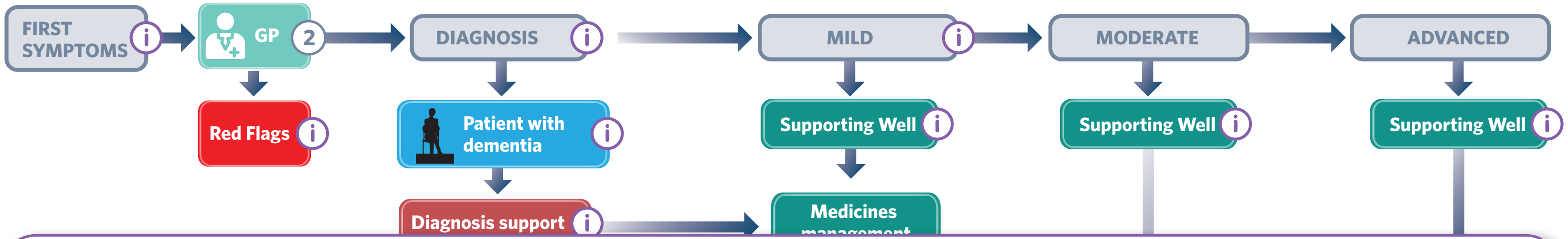

i24 CARE HOME LIST

General Health assessment

☒ Close

Steps to consider when looking for a care home:

- Seek assessment from local authority social services: this will clarify whether or not residential care is needed and what other options might be available.
- Location: use the NHS directory to find homes nearby.
- Check if there are vacancies; consider length of waiting list and immediate availability.
- Will home provide for the patient's individual needs?
- What contact with the community is there?
- What are the visiting arrangements and arrangements for outings?
- Involvement with the care home, e.g. ongoing communication with staff, support groups or regular meetings.
- Safety and security issues including arrangements for supervision.
- Will home meet specific religious, ethnic, cultural, dietary or language needs?
- Is home dementia friendly?
- Look at the brochure and last inspection report

Improving diagnosis in care homes

General Practitioner has key role: Where a care home has dedicated sessions from a specific GP, it is possible to encourage GPs to double check that all the residents that the GP knows have dementia are on the QOF Register.

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.

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i25 AVOIDANCE (1 OF 3)

☒ Close

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)

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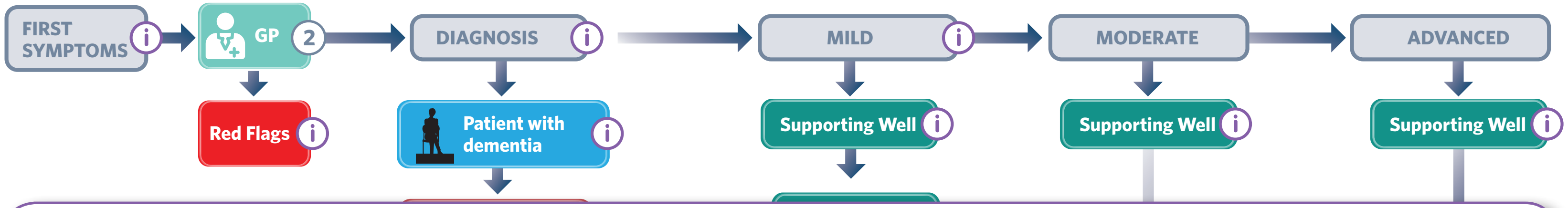

FIRST SYMPTOMS ⓘ → GP ② → DIAGNOSIS ⓘ → MILD ⓘ → MODERATE → ADVANCED

Red Flags ⓘ

Patient with dementia ⓘ

Supporting Well ⓘ

Supporting Well ⓘ

Supporting Well ⓘ

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i25 AVOIDANCE (2 OF 3)

☒ Close

ⓘ

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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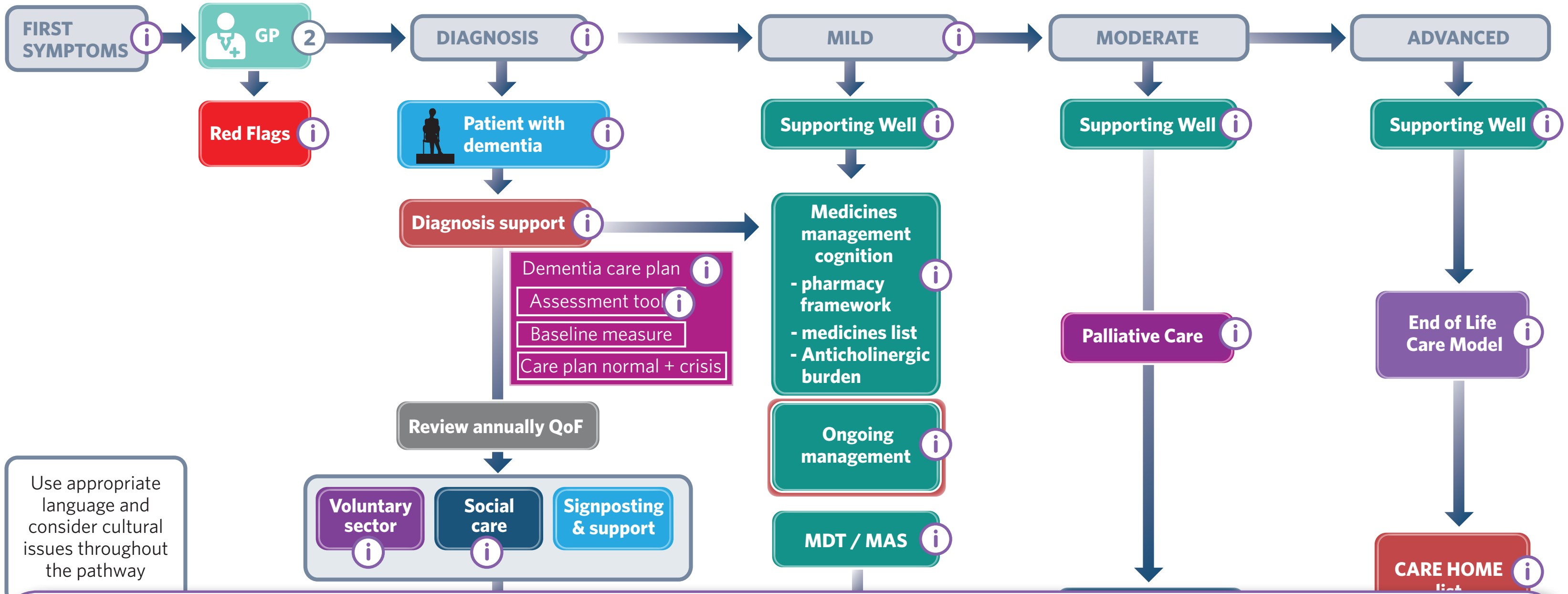

Use appropriate language and consider cultural issues throughout the pathway

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i25 AVOIDANCE (3 OF 3)

☒ Close

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.

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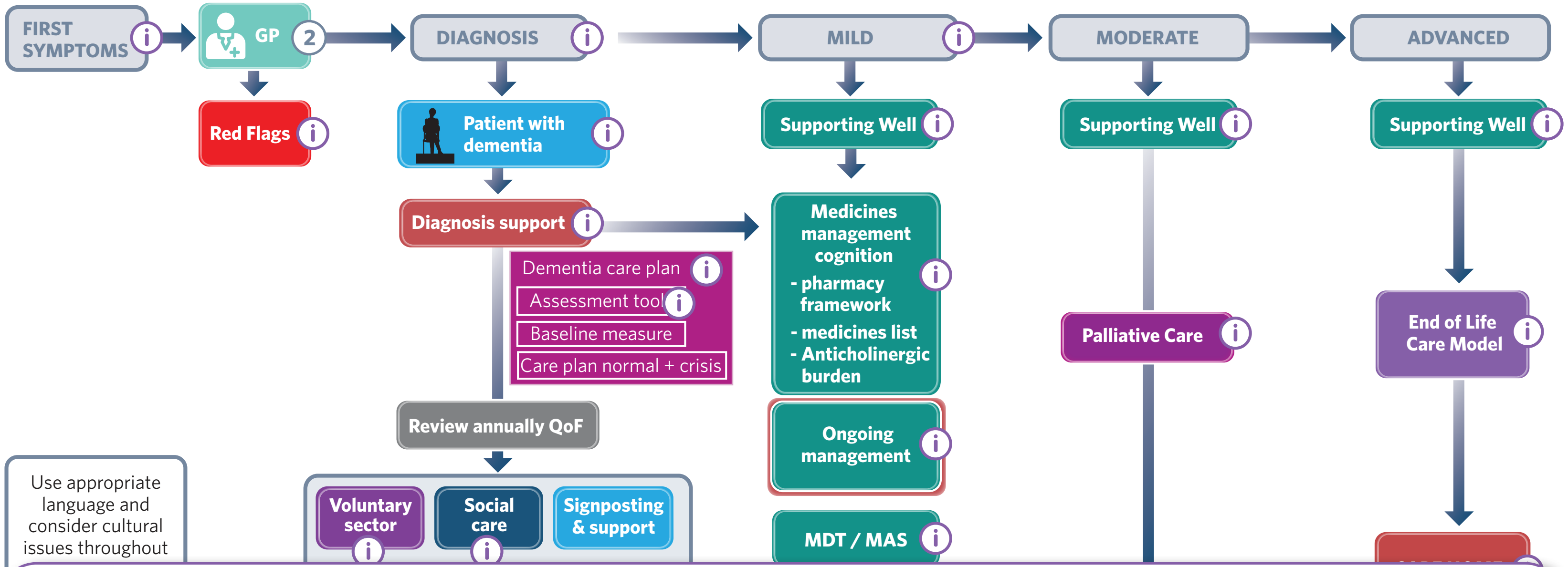

Use appropriate language and consider cultural issues throughout

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i26 MANAGEMENT

☒ Close

Crisis management includes:
- Police
- Ambulance

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

The specifics here are likely locality dependent, so may need to be linked to local services, region by region.

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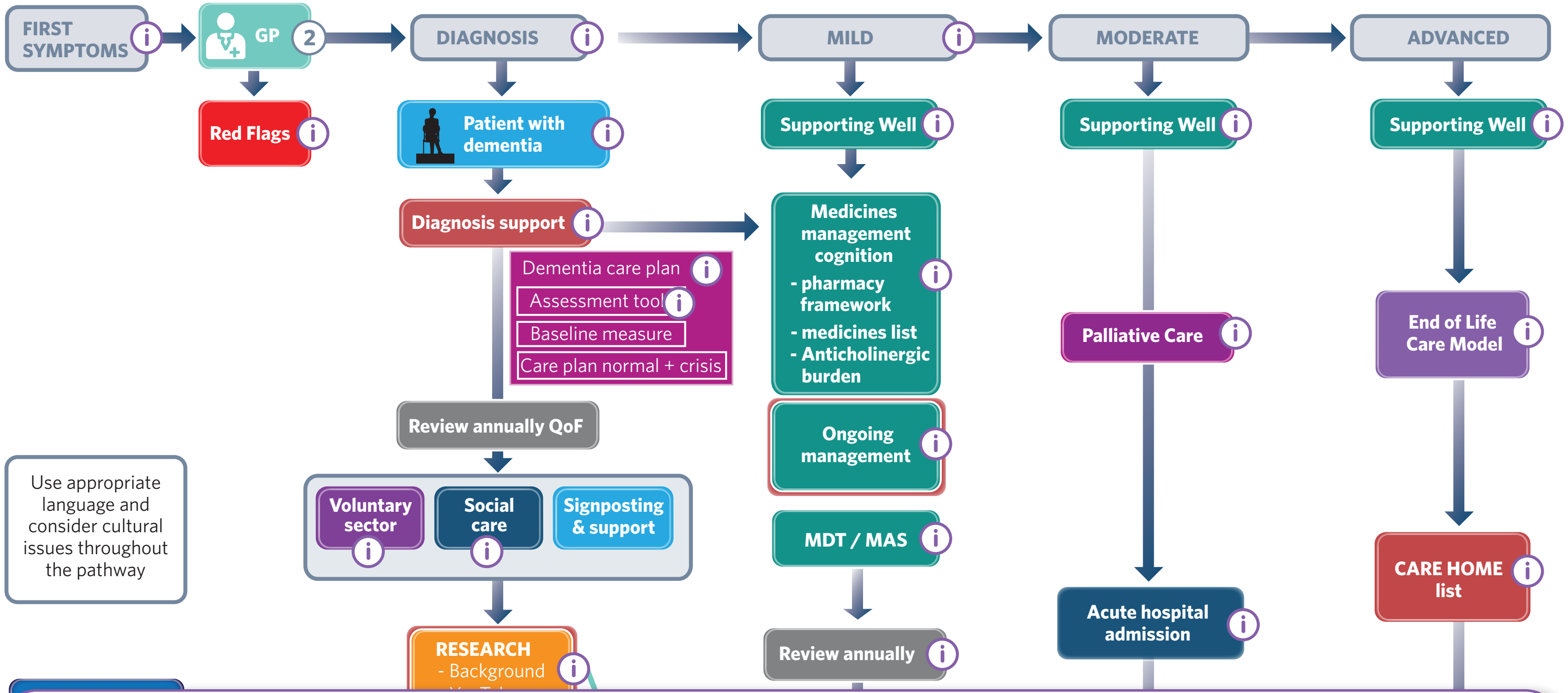

FIRST SYMPTOMS ⓘ → GP ② → DIAGNOSIS ⓘ → MILD ⓘ → MODERATE → ADVANCED

Red Flags ⓘ

Patient with dementia ⓘ

Diagnosis support ⓘ

Dementia care plan ⓘ
Assessment tool ⓘ
Baseline measure
Care plan normal + crisis

Review annually QoF

Voluntary sector ⓘ
Social care ⓘ
Signposting & support

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Supporting Well ⓘ

Medicines management cognition ⓘ
- pharmacy framework
- medicines list
- Anticholinergic burden

Ongoing management ⓘ

MDT / MAS ⓘ

Review annually ⓘ

Supporting Well ⓘ

Palliative Care ⓘ

Acute hospital admission ⓘ

Supporting Well ⓘ

End of Life Care Model ⓘ

CARE HOME list ⓘ

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i27 SUBSEQUENT RESPONSE

☒ Close

Good communication to and from hospital is key – consider whether systems for this are in place.

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)

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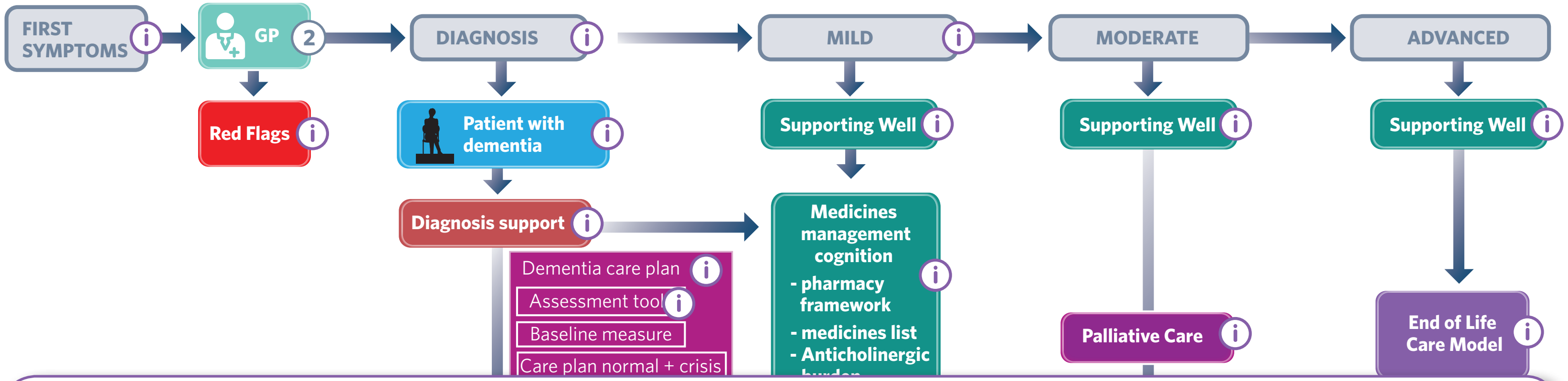

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i28 STAYING WELL THROUGHOUT THE DISEASE

☒ Close

Staying well involves the following quality of life factors:

- Health
- Carer support
- Emotional wellbeing
- 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

Bolton Council Public Health Department has a Staying Well toolkit accessible at:
http://boltonshealthmatters.org/sites/default/files/Staying%20Well%20pilot%20evaluation%20Report2.pdf

Link: Staying_well_poster.pdf

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☒ Close

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.

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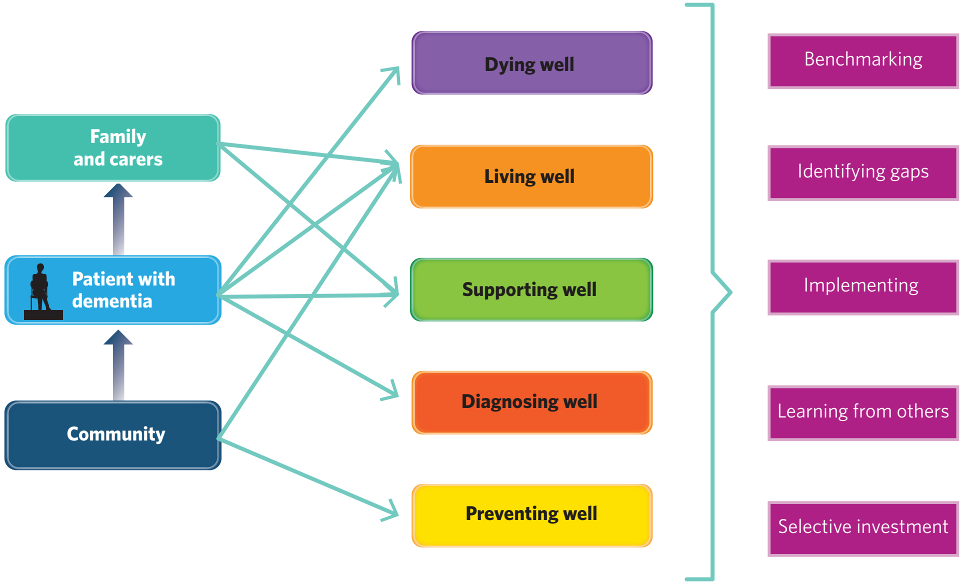
★ Dementia in Sustainability and Transformation Plans (1 of 5)

☒ Close

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



Outcomes and Impact

Achieving/maintaining diagnosis rate

Accessing post diagnostic support and care planning

Maintaining independence in the community

Avoiding unnecessary hospital admission and readmission

Supporting prevention

Encouraging dementia friendly communities

Accessing Cognitive Stimulation Therapy

Enabling appropriate antipsychotic drug prescribing

Facilitating Advance Care Planning

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★ Dementia in Sustainability and Transformation Plans (2 of 5)

☒ Close

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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☒ Close

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

"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)

☒ Close

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.

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★ Dementia in Sustainability and Transformation Plans (5 of 5)

☒ Close

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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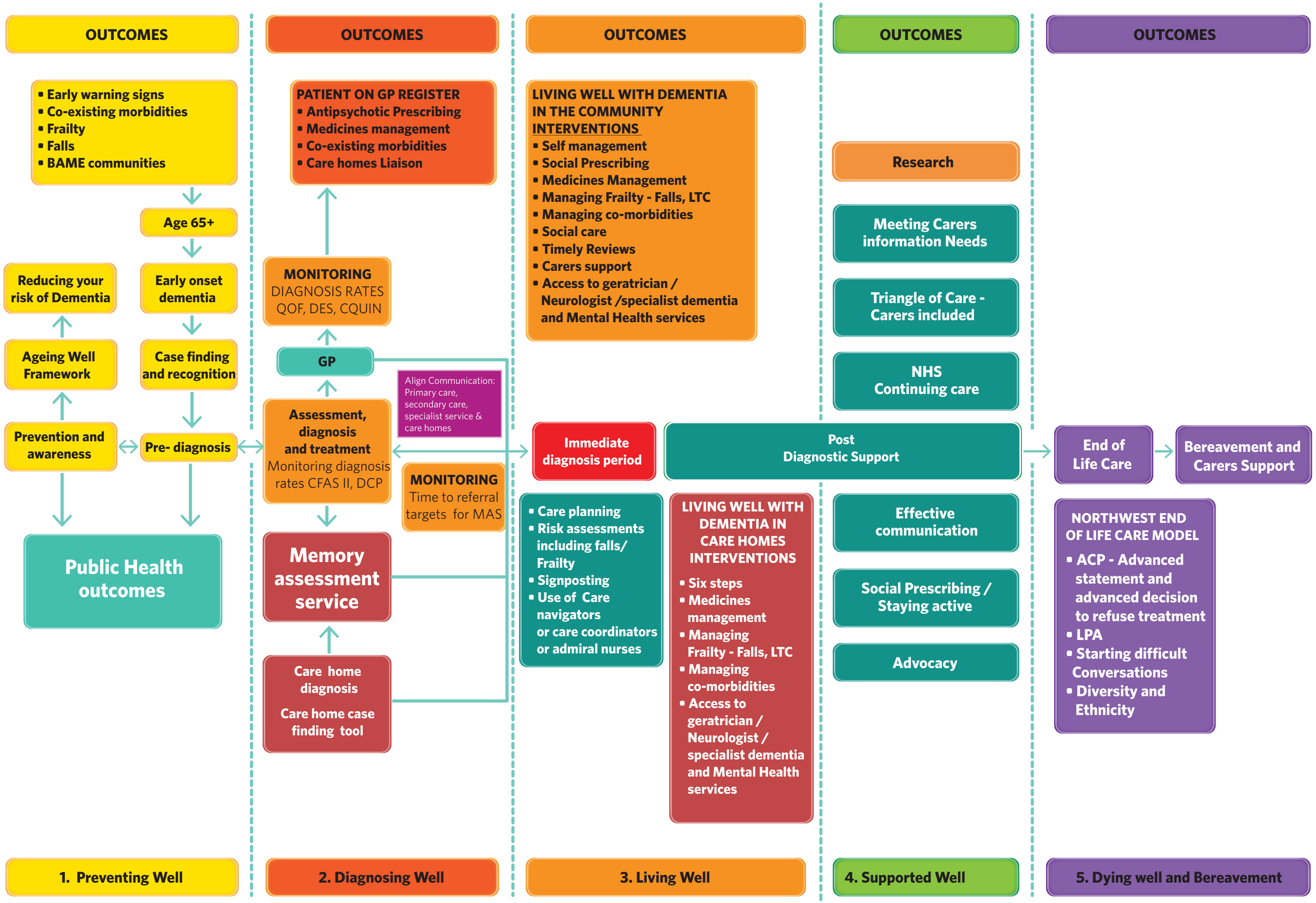

OUTCOMES

- Early warning signs
- Co-existing morbidities
- Frailty
- Falls
- BAME communities

Age 65+

Early onset dementia

Case finding and recognition

Pre- diagnosis

Reducing your risk of Dementia

Ageing Well Framework

Prevention and awareness

Public Health outcomes

1. Preventing Well

OUTCOMES

PATIENT ON GP REGISTER
- Antipsychotic Prescribing
- Medicines management
- Co-existing morbidities
- Care homes Liaison

MONITORING
DIAGNOSIS RATES
QOF, DES, CQUIN

GP

Align Communication: Primary care, secondary care, specialist service & care homes

Assessment, diagnosis and treatment
Monitoring diagnosis rates CFAS II, DCP

MONITORING
Time to referral targets for MAS

Memory assessment service

Care home diagnosis
Care home case finding tool

2. Diagnosing Well

OUTCOMES

LIVING WELL WITH DEMENTIA IN THE COMMUNITY
INTERVENTIONS
- Self management
- Social Prescribing
- Medicines Management
- Managing Frailty - Falls, LTC
- Managing co-morbidities
- Social care
- Timely Reviews
- Carers support
- Access to geratrician / Neurologist /specialist dementia and Mental Health services

Immediate diagnosis period

Post Diagnostic Support

- Care planning
- Risk assessments including falls/ Frailty
- Signposting
- Use of Care navigators or care coordinators or admiral nurses

LIVING WELL WITH DEMENTIA IN CARE HOMES INTERVENTIONS
- Six steps
- Medicines management
- Managing Frailty - Falls, LTC
- Managing co-morbidities
- Access to geratrician / Neurologist / specialist dementia and Mental Health services

3. Living Well

OUTCOMES

Research

Meeting Carers information Needs

Triangle of Care - Carers included

NHS Continuing care

Effective communication

Social Prescribing / Staying active

Advocacy

4. Supported Well

OUTCOMES

End of Life Care

Bereavement and Carers Support

NORTHWEST END OF LIFE CARE MODEL
- ACP - Advanced statement and advanced decision to refuse treatment
- LPA
- Starting difficult Conversations
- Diversity and Ethnicity

5. Dying well and Bereavement

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i1	**SYMPTOMS THAT SIGNIFY ONSET OF DEMENTIA (1 OF 6)**

Memory loss

- Memory loss that disrupts daily life
- Problems with remembering recent events or conversations
- Forgetting appointments
- Constantly misplacing things, or forgetting things like leaving the cooker on
- Difficulty remembering names of people or everyday things
- Repeating things without realising
- Other people starting to notice and comment on forgetfulness

Mental functioning

- Difficulty completing familiar tasks at home, at work or at leisure
- New problems with words in speaking or writing
- Increasing difficulties with activities that need organisation and planning
- Difficulty with numbers and/or handling money in shops
- Finding it hard to follow the thread of conversations or programmes on TV
- Finding it hard to do tasks that need concentration, such as following recipes or instructions
- Problems finding the right words.
- Problems with sleeping and restlessness at night often occur.

Confusion

- Confusion with time or place
- Becoming confused in unfamiliar environments
- Getting lost easily, even in familiar routes
- Feeling disorientated at home, such as repeatedly going into a room and not sure why
- Poor judgement in making decisions, for example managing finances

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SYMPTOMS THAT SIGNIFY ONSET OF DEMENTIA (2 OF 6)

Behaviour

- Out of character behaviour, such as aggression or causing embarrassment in social situations
- Unusual behaviour, such as putting on clothes over pyjamas or putting things in unusual places
- Changes in sleep or appetite patterns
- Changes to level of care in personal grooming, laundry or house cleaning
- People may become increasingly unsteady on their feet and fall more often.
- People gradually require more help with daily activities like dressing, toileting and eating

Personality

- Withdrawal from work or social activities
- Changes in personality, for example used to be shy and quiet, but increasingly loud and boisterous
- Changes in mood, for example feeling anxious, depressed or angry
- Easily upset when out of comfort zone

NHS England Dementia diagnosis and management
(link: https://www.england.nhs.uk/wp-content/uploads/2015/01/dementia-diag-mng-ab-pt.pdf)

CLINICAL FEATURES OF A DEMENTIA SYNDROME

Dementia is a progressive loss of more than one area of cognitive function and is not considered part of normal aging although age is the biggest risk factor for the condition. It is an acquired and chronic state without impairment of consciousness which distinguishes it from learning disabilities and delirium. The signs and symptoms of a dementia syndrome should not be better explained by another process for example another psychiatric condition (depression, psychosis), physical illness or side effects of medication.

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CLINICAL FEATURES OF A DEMENTIA SYNDROME (3 OF 6)

Dementia can be considered as a clinical syndrome with three manifestations

- Neuropsychological, for example
    - Agnosia – memory loss
    - Apraxia – the inability to carry out tasks despite intact sensory and motor systems
    - Agnosia – inability to recognise things
    - Aphasia – difficulty understanding language and using language to express oneself
    - Executive symptoms – planning and organisation, reasoning, judgment

- Activities of Daily Living (ADLs)
    - Changes in cognitive function are often small to start with, but for someone with dementia they have become severe enough to affect their daily social and occupational functioning

- Neuropsychiatric
- Also known as Behavioural and Psychological symptoms of Dementia (BPSD)
- This includes wandering, agitation, aggression, depression, anxiety, psychosis
    - More likely to occur as dementia progresses
    - Often the reason for referral to secondary mental health services and admission

Diagnosing dementia is a two-stage process:

1. First one must decide if there is evidence of a dementia syndrome. Underlying medical and other psychiatric conditions must be ruled out by taking a history, including an informant history where possible, a physical examination and blood tests.
2. From the history and mental state examination it may be possible to identify the likely aetiology of the dementia. Additional investigations may be required for example imaging, detailed and detailed neuropsychological assessment, before the aetiology can be more accurately identified.

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CLINICAL FEATURES OF A DEMENTIA SYNDROME (4 OF 6)

DEMENTIA SUBTYPES

Mild Cognitive Impairment (MCI)

- There must be objective evidence of cognitive impairment which is not normal for age
- No or very little impact on daily activities
- No or very little progression over time
- Over three years, approximately one third of patients with MCI spontaneously improve (suggesting that their symptoms were caused by depression, anxiety or a self-limiting physical illness), one third stay the same, and one third progress to dementia
- Cognitive enhancing medication is not routinely recommended

Alzheimer's Disease Insidious onset of symptoms with a gradual progression over time

- Early symptoms include difficulty with
- remembering new information ('poor short term' memory)
- recalling names of people and places ('word finding difficulties')
- planning and organisation
- disorientation to time and place
- emotional changes

Vascular Dementia

- Presence of vascular risk factors
- There may be a family history of cerebrovascular disease
- Often past history of TIAs and Stroke
- Sudden onset, step-wise presentation – sometimes noticeable after a 'funny do', an episode of illness, or an operation
- Sometimes the steps can be so small the decline appears to be gradual
- Can remain static for long periods of time
- Cognitive problems evident within 3 months of a cerebrovascular event

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CLINICAL FEATURES OF A DEMENTIA SYNDROME (5 OF 6)

DEMENTIA SUBTYPES

Mixed Alzheimer's/Vascular Dementia

- No clear distinction between AD and vascular dementia
- Combination of features

Dementia in Parkinson's Disease

- Parkinson's Disease is present for at least 12 months before the onset of cognitive decline
- One in six patients with Parkinson's Disease develop an associated dementia which tends to become evident around 5-8 years following the diagnosis of PD

Lewy Body Dementia (LBD)

- The onset of cognitive decline and Parkinsonian symptoms occurs within less than 12 months of each other.
- Memory may be well preserved at first but decline becomes evident with time
- The core features of LBD are
  - Fluctuating cognition with noticeable variations in attention and alertness
  - Recurrent, typically well-formed, visual hallucinations
- Spontaneous signs and symptoms of Parkinson's Disease
- Additional features include
  - Arousal at night and REM sleep disorder
  - Severe sensitivity to neuroleptic (antipsychotic) medication
  - Falls
  - Autonomic dysfunction e.g. urinary incontinence, orthostatic hypotension
  - Depression
  - Delusions

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CLINICAL FEATURES OF A DEMENTIA SYNDROME (6 OF 6)

DEMENTIA SUBTYPES

Frontotemporal Dementia (FTD)

- Sometimes called Pick's Disease although strictly speaking Pick's Disease is a rarer and neuropathologically specific sub type of FTD
- Often presents in a younger age group
- Insidious onset with a gradual and slow decline
- Three types: Behavioural Variant FTD
  Primary Progressive Aphasia
  Semantic dementia which are language variants of FTD

Frontotemporal Dementia (FTD)

- Semantic dementia affects ones understanding of the meaning of words and facts hence the name semantic dementia. Speech is fluent but impoverished
- In Primary Progressive Aphasia the meaning of language is preserved but speech becomes non-fluent
- In the language variants other higher cortical functions tend to be well preserved in the early stages

Young onset dementia

Refers to those with onset of dementia before the age of 65 years.

Learning Disabilities

- Individuals with learning disability (LD) are at higher risk of developing dementia
- Association between Down's syndrome and Alzheimer's disease is well recognised
- Requires specialist assessment

References

https://www.england.nhs.uk/wp-content/uploads/2014/09/dementia-revealed-toolkit.pdf
https://www.alzheimers.org.uk
Bart Sheehan, Salman Karim, Alistair Burns, Old Age Psychiatry, Oxford Specialist Handbooks in Psychiatry, Oxford University Press, 2009

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<table>
<tr><td>i2</td><td>DIAGNOSIS
Assessment tools for diagnosis and monitoring in dementia
https://www.england.nhs.uk/wp-content/uploads/2014/09/dementia-revealed-toolkit.pdf</td></tr>
<tr><td>i3</td><td>RED FLAGS FOR GPS SUSPECTING DEMENTIA
First symptoms and red flags that indicate dementia include:
<table>
<tr><th>Dementia with Lewy bodies</th><th>Normal pressure hydrocephalus</th><th>Cortical-basal degeneration</th></tr>
<tr><td>Early depression</td><td>Multiple falls</td><td>Early apraxia</td></tr>
<tr><td>Visual hallucinations</td><td>Gait change</td><td>Unilateral symptoms</td></tr>
<tr><td>Facial expression</td><td>Incontinence</td><td>Alien limb</td></tr>
<tr><td>Autonomic dysfunction</td><td></td><td></td></tr>
</table></td></tr>
<tr><td>i4</td><td>PATIENT WITH DEMENTIA
Baseline “Normal assessment / Care plan - Normal patient details / Crisis support / |Fears patient may have</td></tr>
<tr><td>i5</td><td>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
• Risk factors, prevention and early identification
• Diagnosis and assessment
• Interventions for cognitive and non-cognitive symptoms, and comorbid emotional disorders
• Palliative care
• Support and interventions for carers</td></tr>
</table>

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i5	**SUPPORT AT DIAGNOSIS** **Consider:** • Holistic and person centred care (Whole system approach) • 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 • Commissioner checklist for dementia • What to expect from good quality dementia services
i6	**DEMENTIA CARE PLAN – Sample care plan** Link: SURP care planning template presentation.pdf **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 • Information provision • Future care planning A review might include: • Living with dementia • Cognition and medication • Physical health check • Risks and behaviours • Avoiding unplanned admissions • End of life At the end of the review the GP or clinician will print a patient-held care plan.

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i6	**DEMENTIA CARE PLAN – Sample care plan** Link: SURP care planning template presentation.pdf **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
i7	**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.

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ASSESSMENT TOOLS FOR DIAGNOSIS AND MONITORING IN DEMENTIA (1 OF 4)

Montreal Cognitive Assessment (MoCA)

One page 30 point test

Administered in 10 minutes

Tests several areas of memory including:

- 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

General Practitioner Assessment of Cognition (GP COG)

A brief screening test for cognitive impairment, taking less than 10 minutes, specifically designed for primary care. It consists of:

- 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.

Mini Addenbrooke's Cognitive Assessment (Mini ACE)

A brief cognitive screening tool for dementia.

It is a 30 point test and contains items assessing:

- Orientation
- Memory
- Language
- Visuospatial

The Mini-ACE is derived from the well recognised and validated Addenbrooke's Cognitive Examination which is widely used in secondary care.

Using the Mini –ACE therefore allows for comparison and monitoring from pre-existing ACE data. The Mini-ACE is brief and achievable in a primary care setting

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ASSESSMENT TOOLS FOR DIAGNOSIS AND MONITORING IN DEMENTIA (2 OF 4)

General Practitioner Assessment of Cognition (GP COG)

- **What is the best dementia screening instrument for general practitioners to use? American Journal of Geriatric Psychiatry, 2006. 14(5): p. 391-400** Found the GPCOG was a well validated tool in the community population and GP samples. It was also easy to administer.
- **Brief screening tests for dementia.. Canadian Journal of Psychiatry - Revue Canadienne de Psychiatrie, 2002. 47(8): p. 723-33.**
- **Screening for dementia in primary care: a review of the use, efficacy and quality of measures. International Psychogeriatrics, 2008. 20(5): p. 911-26.**

www.alz.org/documents_custom/gpcog(english).pdf

Mini Addenbrooke's Cognitive Assessment

- **The Mini-Addenbrooke's Cognitive Examination: A New Assessment Tool for Dementia (Hsieh et al).** This compared the Mini-ACE with the MMSE in patients with dementia as well as controls. They included patients with behavioural variant frontotemporal dementia, primary progressive aphasia, Alzheimers dementia and corticobasilar dementia. They used 2 cut off scores (25 and 21). They found that a cut off of 25 had a high sensitivity and specificity, however a cut off of <21 was almost certainly from a patient with dementia. The Mini-ACE was more sensitive than the MMSE and less like to have ceiling effects.

https://lodestone.neura.edu.au/frontier/ace-iii/

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ASSESSMENT TOOLS FOR DIAGNOSIS AND MONITORING IN DEMENTIA (3 OF 4)

Montreal Cognitive Assessment

- **MoCA versus MMSE as screening tool for diagnosing cognitive impairment in a memory clinic setting – A.J.Lamer (Walton Neurology Centre, Liverpool, UK)**. The study found the MoCA was accebptable, quick and easy to use. Using a cut off of < 26/30, it was more sensitive to then MMSE with better diagnostic accuracy. However it was less specific than the MMSE.
- **Evaluating the MoCA and Mini Mental State Exam for Cognitive Impairment Post Stroke – Lauren Friedman (University of Western Ontario).** Found that the MoCA demonstrated slightly better diagnostic accuracy then the MMSE and was a more sensitive tool
- **Cross validation of MoCA in community dwelling older adults residing in Southeastern US (Luis CA, Keegan AP, Mullan M).** MoCA appears to have utility for early detection of mild cognitive impairment and Alzheimers dementia. With cut off of <26/30 it detected 97% of those with cognitive impairment but with a specificity of 35%. Using a lower cut off of 23 resulted in both excellent sensitivity and specificity (96% and 95% respectively).
- **MoCA: validation study for Vascular Dementia (Freitas S, Simões MR, Alves L, Vicente M, Santana I). F**ound MoCA a valid, sensitive, reliable and accurate screening tool for patients with vascular dementia. MMSE and MoCA in Parkinson's disease and dementia with Lewy bodies: a multicenter 1-year follow-up study (Biundo R et al). Retrospective cohort study measuring MMSE and MoCA at baseline and 1 year. Found both to be equal in measuring rate of cognitive decline.

www.mocatest.org/pdf_files/test/MoCA-Test-English_7_1.pdf

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General Practitioner Assessment of Cognition (GP COG) (4 OF 4)

- **What is the best dementia screening instrument for general practitioners to use? American Journal of Geriatric Psychiatry, 2006. 14(5): p. 391-400** Found the GPCOG was a well validated tool in the community population and GP samples. It was also easy to administer.
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i8	**VOLUNTARY SECTOR** Link: https://www.alzheimers.org.uk/
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) SCIE Guide 47 - Personalisation: a rough guide (SCIE, 2012) SCIE Guide 52 - GP services for older people: a guide for care home managers (SCIE, 2013)
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/
i11	**RESEARCH** **Dendron** Link: https://www.crn.nihr.ac.uk/dementia/about-dementia-research/research/ **Join Dementia Research** Link: https://www.joindementiaresearch.nihr.ac.uk/

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MILD - MEDICINES MANAGEMENT TABLE (1 OF 3)

	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	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 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.			

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MILD - MEDICINES MANAGEMENT TABLE (2 OF 3)

	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, COPD, cardiac conduction abnormalities, peptic ulcers, seizures.			Hx of seizures

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ANTICHOLINERGIC BURDEN (ACB) (3 OF 3)

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).

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

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

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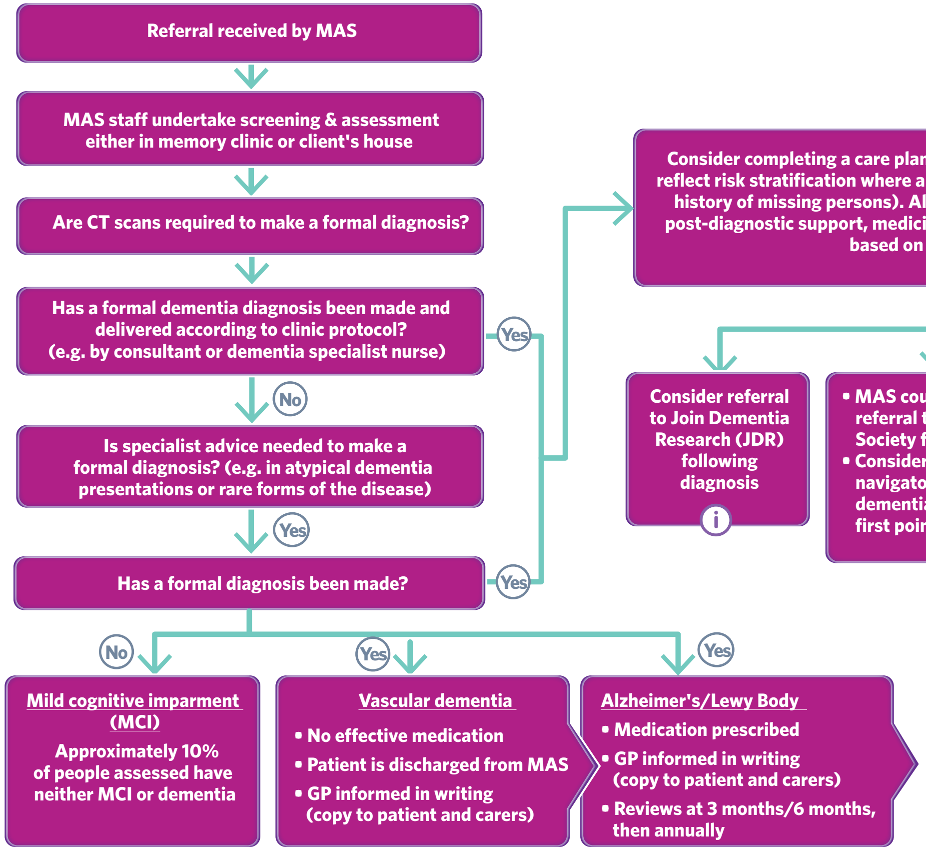
i13 **Ongoing Management**

Add in short summary of MDT OT Psychology

i14 **Memory Assessment Services (MAS) (1 OF 5)**



Referral received by MAS

MAS staff undertake screening & assessment either in memory clinic or client's house

Are CT scans required to make a formal diagnosis?

Has a formal dementia diagnosis been made and delivered according to clinic protocol? (e.g. by consultant or dementia specialist nurse)

Yes

No

Is specialist advice needed to make a formal diagnosis? (e.g. in atypical dementia presentations or rare forms of the disease)

Yes

Has a formal diagnosis been made?

Yes

Consider completing a care plan/care support plan for the patient to reflect risk stratification where appropriate (e.g. long-term conditions, history of missing persons). Also consider immediate and ongoing post-diagnostic support, medicines management and timely reviews based on need and risk.

Consider referral to Join Dementia Research (JDR) following diagnosis

- MAS could make referral to Alzheimer's Society for support
- Consider use of care navigators or dementia advisor as first point of contact

- Access to ommediate and ongoing post diagnostic support for patients, carers and their families to:
- Understand patient's & carers' needs
- Offer advice & signposting

No

Yes

Yes

Mild cognitive imparment (MCI)

Approximately 10% of people assessed have neither MCI or dementia

Vascular dementia

- No effective medication
- Patient is discharged from MAS
- GP informed in writing (copy to patient and carers)

Alzheimer's/Lewy Body

- Medication prescribed
- GP informed in writing (copy to patient and carers)
- Reviews at 3 months/6 months, then annually

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Service Specification for Memory Assessment Services (MAS) (2 of 5)

- 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/

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i14	**CT scanning and the impact on diagnosis (3 of 5)** - 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/ **Service Specification for Memory Assessment Services (MAS)** **Mild Cognitive Impairment (MCI)** 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/)

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i14	**Best practice and tips for medicines management (see NICE guidance CG42 for more information) (4 of 5)** • 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 **Links to other services** Suggestions from the MAS for GP referral to stroke clinic or vascular services

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i14	**Service Specification for Memory Assessment Services (MAS) (5 of 5)** **Annual Review** • 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** Suggestions from the MAS for GP referral to stroke clinic or vascular services
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 A review might include: • Living with dementia • Cognition and medication • Physical health check • Risks and behaviours • Avoiding unplanned admissions • End of life.

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i16	**Life Events to consider /NOT IN CRISIS** Driving / Travel / moving care home /Legal POA
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 • Training and Support for staff and Families • Treatment advice out of hospital • Effective Signposting • Timely Reviews • Telecare • Housing • Safety and Security • Education and better understanding of the condition can help support better patient care by directing patients, their carers and families to the appropriate services • Clear Roles and Responsibilities needed for appropriate signposting - consider the various tiers of training and health and social care groups where appropriate.
i18	**PALLIATIVE CARE** A guide to symptom management in palliative care: Link: https://www.yorkhospitals.nhs.uk/document.php?o=2360

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i19	**CRISIS - POLICE** Links: Herbert protocol leaflet.pdf Dementia guardian leaflet.pdf Dementia leaflet.pdf Link: Voluntary sector  Look Out For This Logo DEMENTIA BUDDY On Any Of These Devices Guardian Angels 'Tap Your NFC Enabled Phone To Get Them Home' IN CASE OF EMERGENCY CONTACT DETAILS DEMENTIA DON'T STALL, MAKE THE CALL WHAT TO DO WHEN A PERSON WITH DEMENTIA GOES MISSING CALL 101 POLICE
i20	**CRISIS -AMBULANCE (1 OF 2)** **Message in a bottle** '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.

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i20	**CRISIS -AMBULANCE** **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
i21	**ACUTE HOSPITAL ADMISSION** Preventing avoidable emergency admissions to acute general hospitals • Programmes to help prevent admissions include: • Case management • Crisis resolution teams • Intermediate care • Telehealth • Team-based interventions in A&E • Proactive management of long-term conditions • Evidence around renewed slips, trips and falls initiatives, particularly targeted at older people with dementia is required Link: http://www.yhpho.org.uk/resource/view.aspx?RID=207311

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CARER SUPPORT

Carers:

- Have a legal right to an assessment of their needs
- 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 with regards to assessment and referral
- 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.
- Should also be able to self-refer for an assessment.

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

i23

END OF LIFE CARE MODEL (1 of 3)

The model comprises five phases which identifies key elements of practice within each phase. The model supports the assessment and planning process for patients from the diagnosis of the life-limiting illness or those who may be frail.

For further details about good practice in palliative care visit:

National Council for Palliative Care, http://www.ncpc.org.uk
Health Education England, hee.nhs.uk
NHS England, www.england.nhs.uk

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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
• 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

ADRT - Advance Decision to Refuse Treatment
DNACPR - Do Not Attempt Cardio Pulmonary Resuscitation
EPaCCS - Electronic Palliative Care Coordinating System
GP - General Practitioner
ICD - Implantable Cardioverter Defibrillator
NWAS - North West Ambulance Service
OOH - Out of Hours
PPC - Preferred Priorities of Care

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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
• 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	• Ongoing communication with 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 and when necessary • ICD discussion and deactivation	• 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

ADRT - Advance Decision to Refuse Treatment
DNACPR - Do Not Attempt Cardio Pulmonary Resuscitation
EPaCCS - Electronic Palliative Care Coordinating System
GP - General Practitioner
ICD - Implantable Cardioverter Defibrillator
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i24	**CARE HOME LIST** General Health assessment **Steps to consider when looking for a care home:** • Seek assessment from local authority social services: this will clarify whether or not residential care is needed and what other options might be available. • Location: use the NHS directory to find homes nearby. • Check if there are vacancies; consider length of waiting list and immediate availability. • Will home provide for the patient's individual needs? • What contact with the community is there? • What are the visiting arrangements and arrangements for outings? • Involvement with the care home, e.g. ongoing communication with staff, support groups or regular meetings. • Safety and security issues including arrangements for supervision. • Will home meet specific religious, ethnic, cultural, dietary or language needs? • Is home dementia friendly? • Look at the brochure and last inspection report **Improving diagnosis in care homes** **General Practitioner** has key role: Where a care home has dedicated sessions from a specific GP, it is possible to encourage GPs to double check that all the residents that the GP knows have dementia are on the QOF Register. **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.

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i25	AVOIDANCE (1 OF 3)

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.

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)

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AVOIDANCE (2 OF 3)

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 feature. 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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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.
i26	**MANAGEMENT** Crisis management includes: • Police • Ambulance 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 The specifics here are likely locality dependent, so may need to be linked to local services, region by region.

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i27	**SUBSEQUENT RESPONSE** Good communication to and from hospital is key – consider whether systems for this are in place. 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)
i28	**STAYING WELL THROUGHOUT THE DISEASE** Staying well involves the following quality of life factors: • Health • Carer support • Emotional wellbeing • 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 Bolton Council Public Health Department has a Staying Well toolkit accessible at: http://boltonshealthmatters.org/sites/default/files/Staying%20Well%20pilot%20evaluation%20Report2.pdf Link: Staying_well_poster.pdf

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Nice Dementia Pathway

NICE (2015) Guideline [NH16] Dementia Disability and Frailty in Later Life – Mid Life Approaches to Delay or Prevent Onset NICE London

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NHS
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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Dr Trevor Crawford

Join Dementia Research. Information can be found here

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Lancashire Care Foundation Trust

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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.
  - **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.

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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 Issue 8 (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 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.

This guidance 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 here

The Tiers of training identified are summarised below:

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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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☒ Close

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?		
c.	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		
a.	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 here.

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 here

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

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

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.

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

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 towards research participation	Effective way to change attitudes towards research participation
Can be done at any time before, during or after consultation/activity	Can be done at any time
Extensive resources available	Extensive resources available
Able to evaluate whether the process has worked	Able to evaluate whether the process has worked
Cons	
Perceived as more time consuming	Difficult to establish whether attendees have understood the content
Might incur additional resource –time and staff cost	Not tailored to specific need and may need further clarification
Reliance on staff knowledge and understanding	Attendees may not have the opportunity to ask further questions

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 here 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

WEST YORKSHIRE POLICE

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

Next

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 money?		if so how much?	
Bank details		Bus pass; Name: Number:	

Previous places found:

Description of what the person was wearing; include colour, designer label/brands

Shirt/Sweater	
Trousers/Skirt	
Outerwear e.g. coat, jacket	
Headwear	
Gloves	
Scarf	
Footwear	
Jewellery e.g. watch, rings	
Other	

Time. date and location last seen:

Risk Factors (please circle): suicidal / depressive / confused / alcohol / violent / other (describe).....

Media release: Yes/No On call manager aware: Yes/No

Any other information that may be of help to the police

Completed by	
Relationship to the person	

Date:

Close

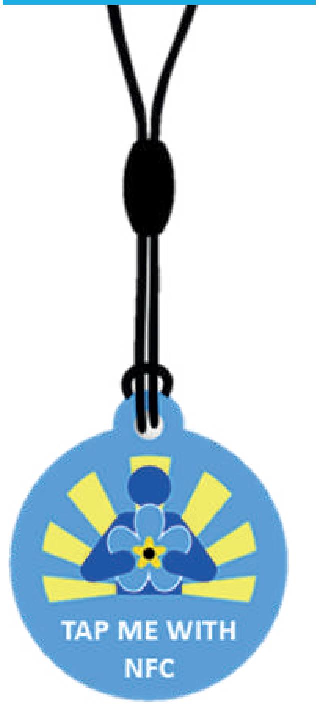
Look Out For This Logo

On Any Of These Devices

Pin Badge

Key Ring

Bag/Zip Tag



Wrist Band

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.

GETTING TO KNOW YOU

GREATER MANCHESTER
POLICE

Next

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

1 **Name of person: (Name they like to be known as)**

2 **Sex:** **MALE / FEMALE**

3 **Date of birth:**

4 **Height:**

5 **Build:**

6 **Hair colour/style:**

7 **Glasses:** **YES / NO**

8 **Ethnic origin:**

9 **Previous home address/addresses:**

10 **Places likely to visit (in present day and from the past)**
Previous workplace/church/schools/churchyard etc.

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

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

13 **Health concerns:**

14 **Medication being taken:**

15 **Implications of NOT having medicines?**

16 **How mobile are they?**

17 **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

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Close

Medications Reviewed in 2012 Update

Medications Added with Score of 1:
Aripiprazole (Abilify™)
Asenapine (Saphris™)
Cetirizine (Zyrtec™)
Clidinium (Librax™)
Desloratadine (Clarinex™)
Iloperidone (Fanapt™)
Levocetirizine (Xyzal™)
Loratadine (Claritin™)
Paliperidone (Invega™)
Venlafaxine (Effexor™)

Medications Added with Score of 2:
Nefopam (Nefogesic™)

Medications Added with Score of 3:
Doxylamine (Unisom™, others)
Fesoterodine (Toviaz™)
Propiverine (Detrunorm™)
Solifenacin (Vesicare™)
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.

Complete References:

1. Boustani MA, Campbell NL, Munger S, Maidment I, Fox GC. Impact of anticholinergics on the aging brain: a review and practical application. Aging Heatlh. 2008;4(3):311-320.
2. Campbell N, Boustani M, Limbil T, et al. The cognitive impact of anticholinergics: a clinical review. Clinical Interventions in Aging. 2009;4(1):225-233.
3. Campbell N, Boustani M, Lane K, et al. Use of anticholinergics and the risk of cognitive impairment in an African-American population. Neurology. 2010;75:152-159.
4. Fox C, Richardson K, Maidment I, et al. Anticholinergic medication use and cognitive impairment in the older population: the Medical Research Council Cognitive Function and Ageing Study. Journal of the American Geriatric Society. 2011; 59(8): 1477-1483.
5. Cai X, Campbell N, Khan B, Callahan C, Boustani M. Long-term anticholinergic use and the aging brain. Alzheimers Dementia. 2012; epub ahead of print.

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/abc-anticholinergic-cognitive-burden-scale.

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

Aging Brain Care

ANTICHOLINERGIC COGNITIVE BURDEN SCALE

2012 Update

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

Regenstrief Institute

IDND FROM DISCOVERY TO DELIVERY.

THE NEW WISHARD

ESKENAZI HEALTH

Next

☒ Close

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™
Iloperidone	Fanapt™
Isosorbide	Isordil™, 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™, Uniphyl™
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

Drugs with ACB Score of 3

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™

Back

NHS

Yorkshire and the Humber
Clinical Networks

Care Planning
Yorkshire & the Humber

Nicola Phillis

Nicola.Phillis@nhs.net

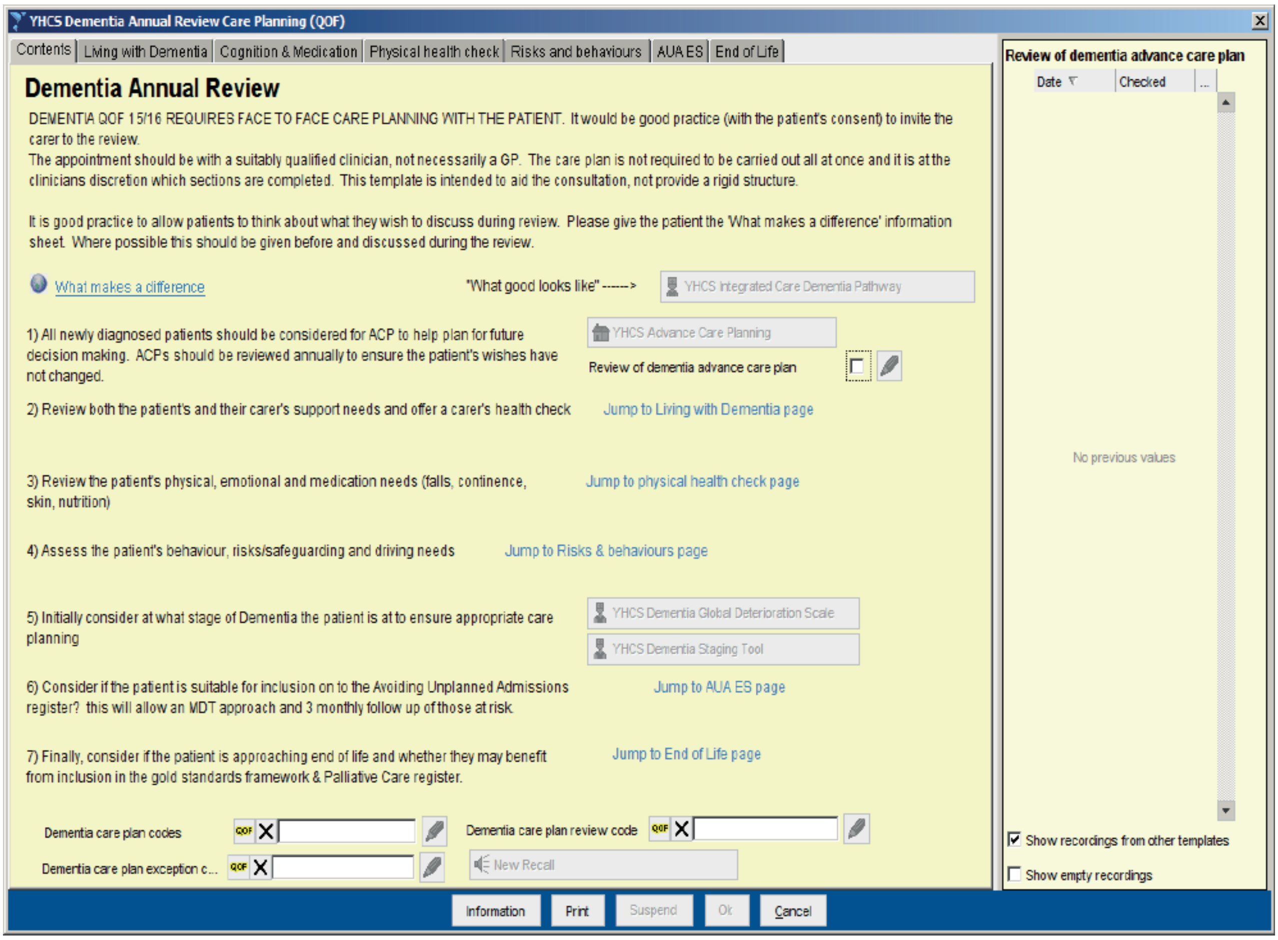
Care Planning Resources

- 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.

Next

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.



Dementia Annual Review

DEMENTIA QOF 15/16 REQUIRES FACE TO FACE CARE PLANNING WITH THE PATIENT. It would be good practice (with the patient's consent) to invite the carer to the review.
The appointment should be with a suitably qualified clinician, not necessarily a GP. The care plan is not required to be carried out all at once and it is at the clinicians discretion which sections are completed. This template is intended to aid the consultation, not provide a rigid structure.

It is good practice to allow patients to think about what they wish to discuss during review. Please give the patient the 'What makes a difference' information sheet. Where possible this should be given before and discussed during the review.

What makes a difference

"What good looks like" ------> YHCS Integrated Care Dementia Pathway

1) All newly diagnosed patients should be considered for ACP to help plan for future decision making. ACPs should be reviewed annually to ensure the patient's wishes have not changed. — YHCS Advance Care Planning — Review of dementia advance care plan ☐

2) Review both the patient's and their carer's support needs and offer a carer's health check — Jump to Living with Dementia page

3) Review the patient's physical, emotional and medication needs (falls, continence, skin, nutrition) — Jump to physical health check page

4) Assess the patient's behaviour, risks/safeguarding and driving needs — Jump to Risks & behaviours page

5) Initially consider at what stage of Dementia the patient is at to ensure appropriate care planning — YHCS Dementia Global Deterioration Scale — YHCS Dementia Staging Tool

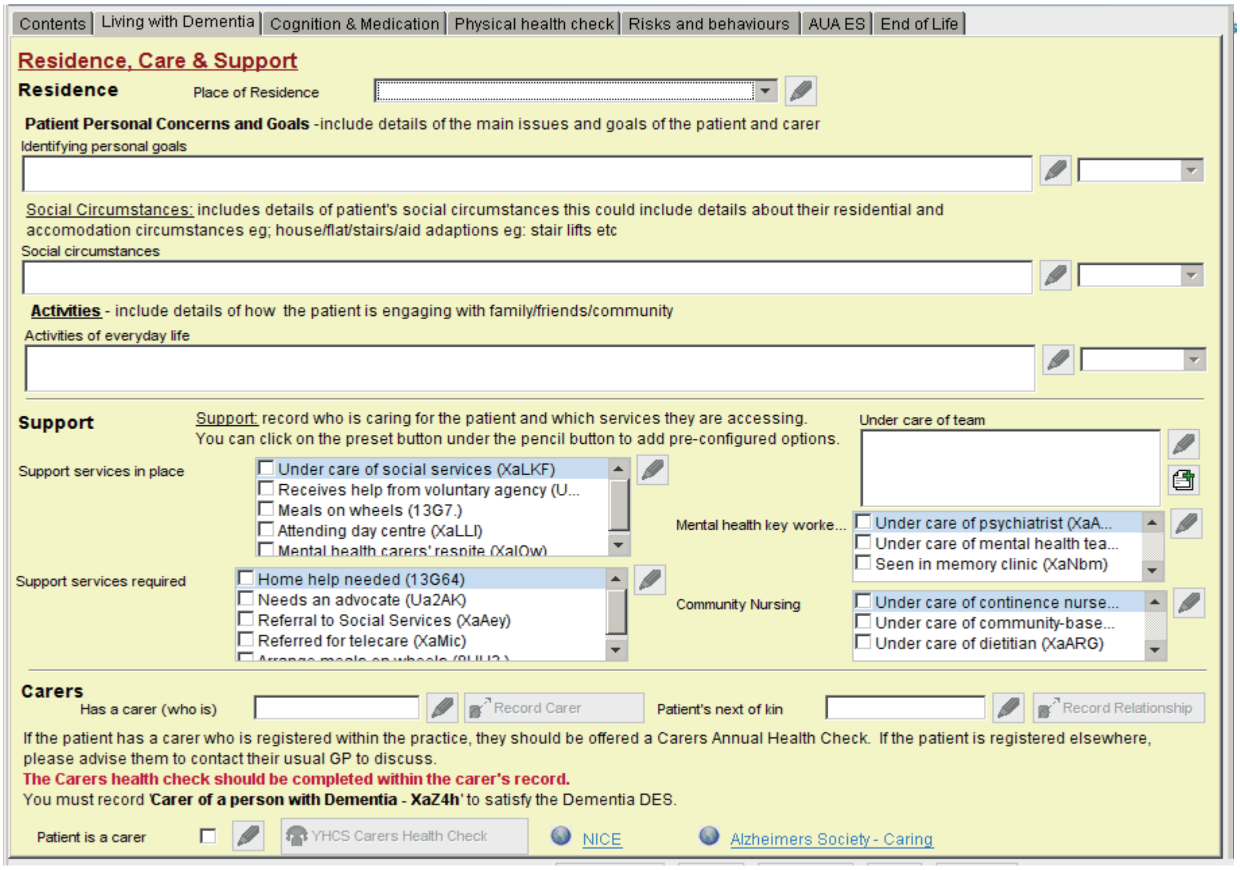
6) Consider if the patient is suitable for inclusion on to the Avoiding Unplanned Admissions register? this will allow an MDT approach and 3 monthly follow up of those at risk — Jump to AUA ES page

7) Finally, consider if the patient is approaching end of life and whether they may benefit from inclusion in the gold standards framework & Palliative Care register. — Jump to End of Life page

Dementia care plan codes QOF ☒
Dementia care plan review code QOF ☒
Dementia care plan exception c... QOF ☒
New Recall

☑ Show recordings from other templates
☐ Show empty recordings

READ CODE 'HEAVY' VERSION



Residence, Care & Support

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: includes 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 (XaLKF)
- ☐ Receives help from voluntary agency (U...
- ☐ Meals on wheels (13G7.)
- ☐ Attending day centre (XaLLI)
- ☐ Mental health carers' respite (XaIOw)

Support services required
- ☐ Home help needed (13G64)
- ☐ Needs an advocate (Ua2AK)
- ☐ Referral to Social Services (XaAey)
- ☐ Referred for telecare (XaMic)
- ☐ Arrange meals on wheels (8HJ3.)

Under care of team

Mental health key worke...
- ☐ Under care of psychiatrist (XaA...
- ☐ Under care of mental health tea...
- ☐ Seen in memory clinic (XaNbm)

Community Nursing
- ☐ Under care of continence nurse...
- ☐ Under care of community-base...
- ☐ Under care of dietitian (XaARG)

Carers

Has a carer (who is)

Patient's next of kin

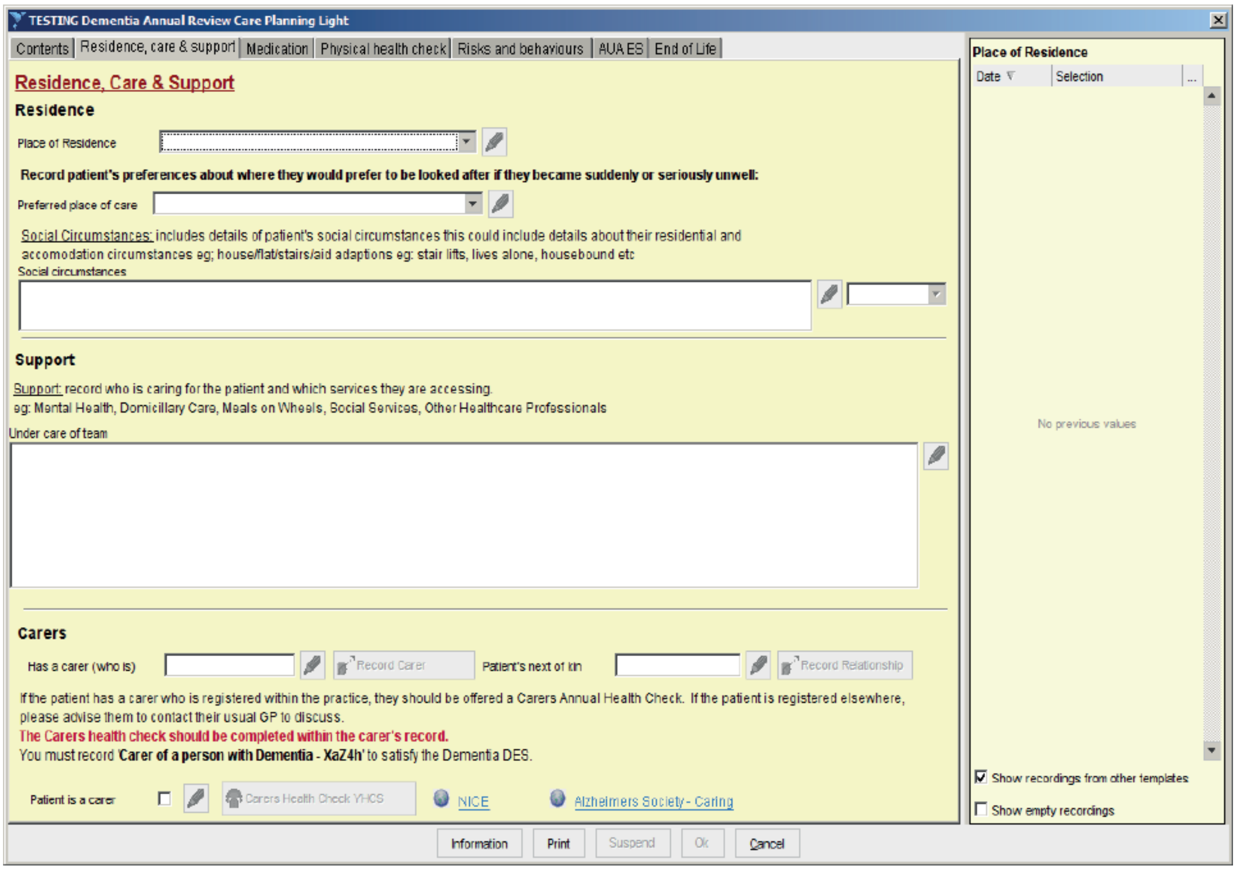
If the patient has a carer who is registered within the practice, they should be offered a Carers Annual Health Check. If the patient is registered elsewhere, please advise them to contact their usual GP to discuss.

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 ☐

LIGHT VERSION



Residence, Care & Support

Residence

Place of Residence

Record patient's preferences about where they would prefer to be looked after if they became suddenly or seriously unwell:

Preferred place of care

Social Circumstances: includes 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, lives alone, housebound etc

Social circumstances

Support

Support: record who is caring for the patient and which services they are accessing.
eg: Mental Health, Domicillary Care, Meals on Wheels, Social Services, Other Healthcare Professionals

Under care of team

Carers

Has a carer (who is)

Patient's next of kin

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 elsewhere, please advise them to contact their usual GP to discuss.

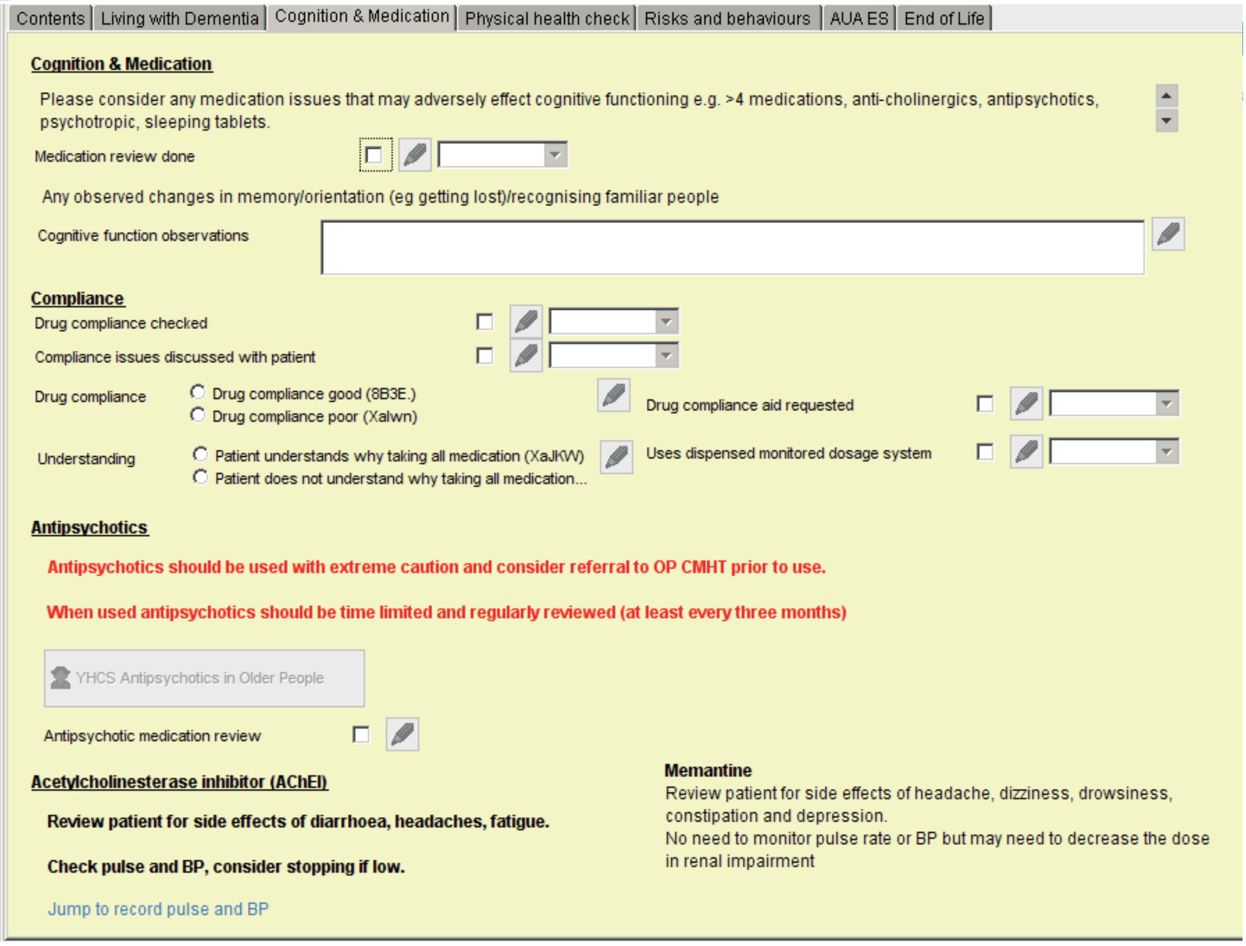
The Carers health check should be completed within the carer's record.

You must record '**Carer of a person with Dementia - XaZ4h**' to satisfy the Dementia DES.

Patient is a carer ☐

☑ Show recordings from other templates

☐ Show empty recordings



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
○ Drug compliance good (8B3E.)
○ Drug compliance poor (Xalwn)

Drug compliance aid requested ☐

Understanding
○ Patient understands why taking all medication (XaJKW)
○ Patient does not understand why taking all medication...

Uses dispensed monitored dosage system ☐

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)

Antipsychotic medication review ☐

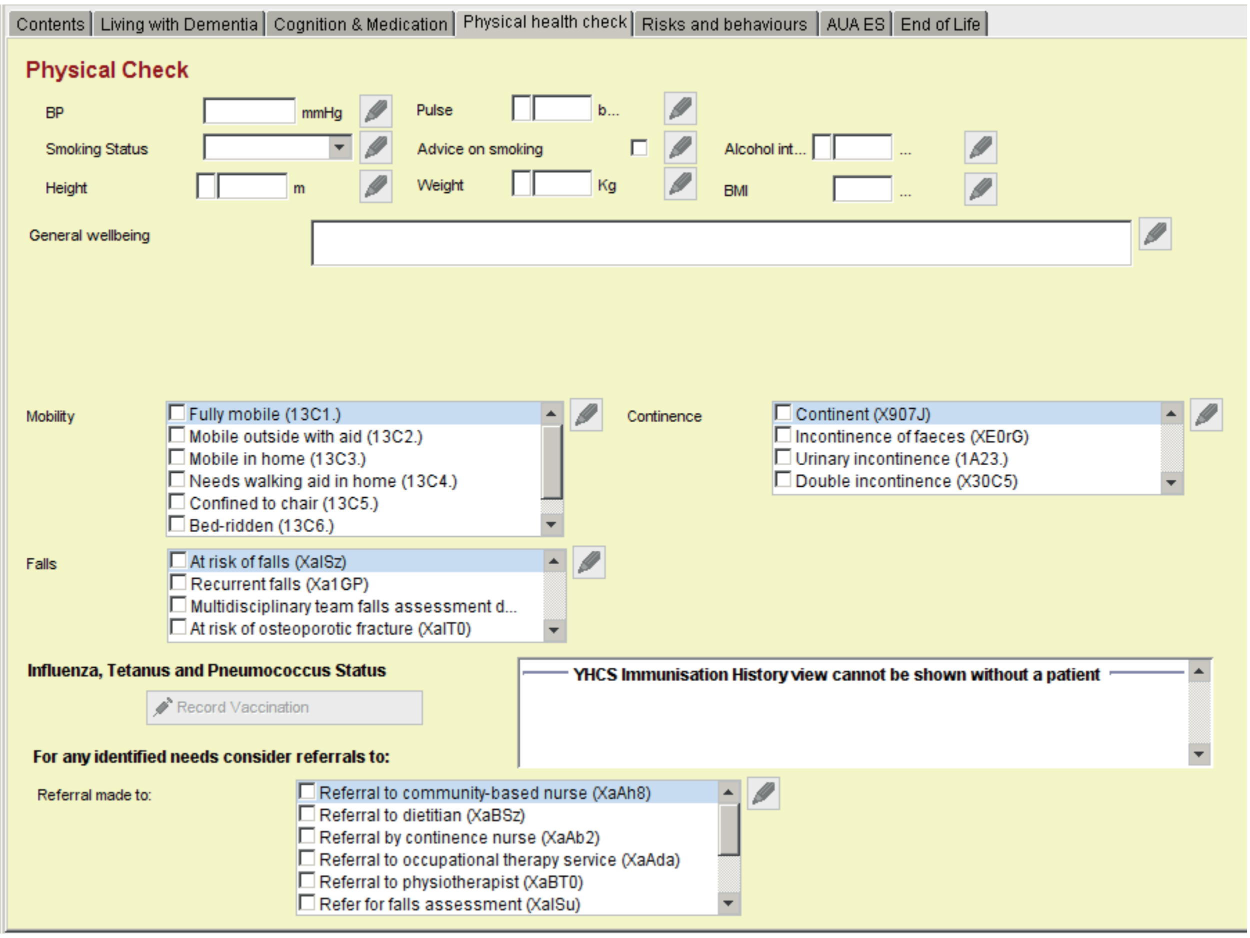
Acetylcholinesterase inhibitor (AChEI)

Review patient for side effects of diarrhoea, headaches, fatigue.

Check pulse and BP, consider stopping if low.

Jump to record pulse and BP

Memantine
Review patient for side effects of headache, dizziness, drowsiness, constipation and depression.
No need to monitor pulse rate or BP but may need to decrease the dose in renal impairment



Physical Check

BP mmHg

Pulse b...

Smoking Status

Advice on smoking ☐

Alcohol int... ...

Height m

Weight Kg

BMI ...

General wellbeing

Mobility
☐ Fully mobile (13C1.)
☐ Mobile outside with aid (13C2.)
☐ Mobile in home (13C3.)
☐ Needs walking aid in home (13C4.)
☐ Confined to chair (13C5.)
☐ Bed-ridden (13C6.)

Continence
☐ Continent (X907J)
☐ Incontinence of faeces (XE0rG)
☐ Urinary incontinence (1A23.)
☐ Double incontinence (X30C5)

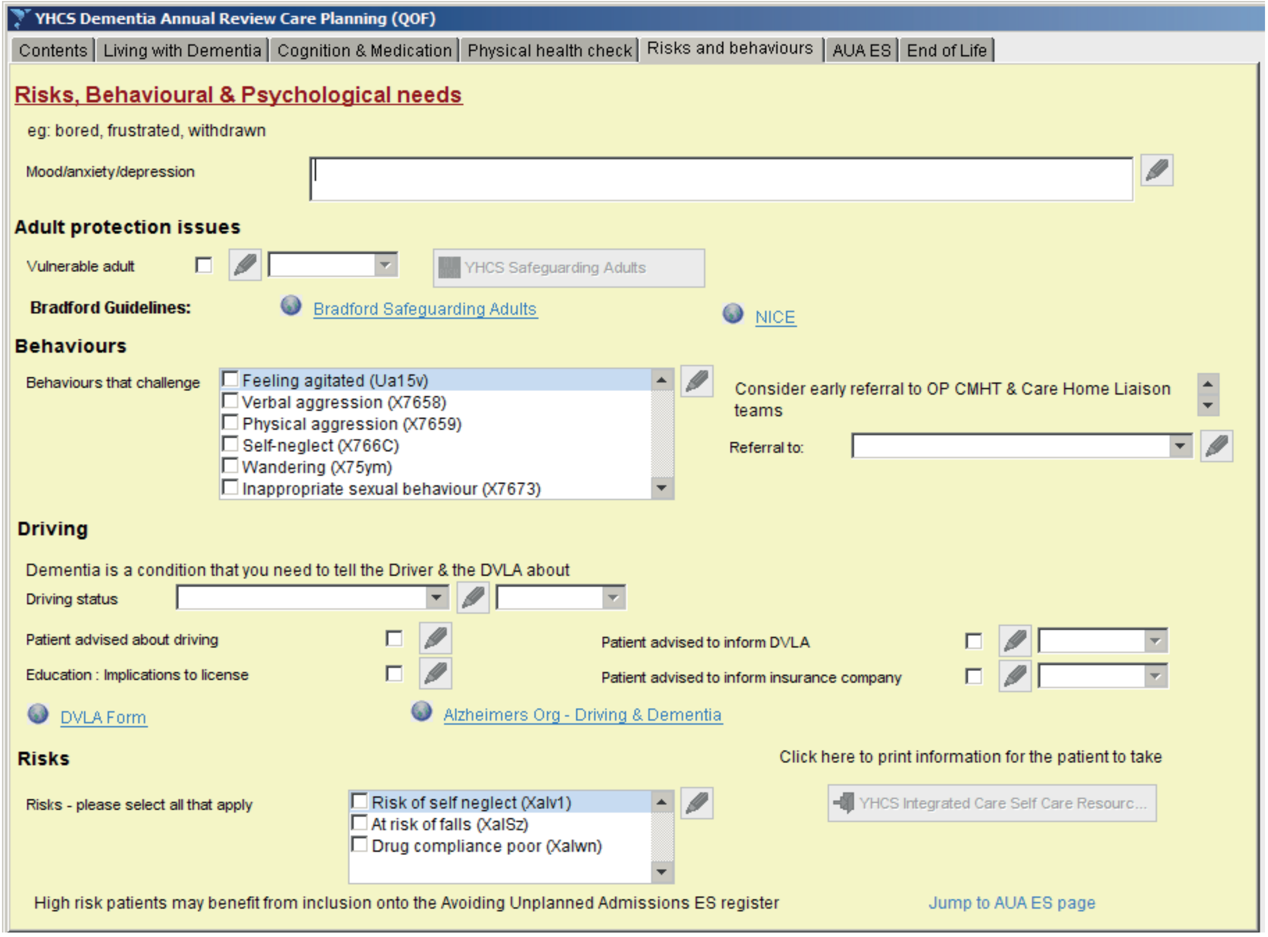
Falls
☐ At risk of falls (XaISz)
☐ Recurrent falls (Xa1GP)
☐ Multidisciplinary team falls assessment d...
☐ At risk of osteoporotic fracture (XaIT0)

Influenza, Tetanus and Pneumococcus Status

YHCS Immunisation History view cannot be shown without a patient

For any identified needs consider referrals to:

Referral made to:
☐ Referral to community-based nurse (XaAh8)
☐ Referral to dietitian (XaBSz)
☐ Referral by continence nurse (XaAb2)
☐ Referral to occupational therapy service (XaAda)
☐ Referral to physiotherapist (XaBT0)
☐ Refer for falls assessment (XaISu)



Risks, Behavioural & Psychological needs

eg: bored, frustrated, withdrawn

Mood/anxiety/depression

Adult protection issues

Vulnerable adult ☐

Bradford Guidelines: Bradford Safeguarding Adults NICE

Behaviours

Behaviours that challenge
- ☐ Feeling agitated (Ua15v)
- ☐ Verbal aggression (X7658)
- ☐ Physical aggression (X7659)
- ☐ Self-neglect (X766C)
- ☐ Wandering (X75ym)
- ☐ Inappropriate sexual behaviour (X7673)

Consider early referral to OP CMHT & Care Home Liaison teams

Referral to:

Driving

Dementia is a condition that you need to tell the Driver & the DVLA about

Driving status

Patient advised about driving ☐

Education : Implications to license ☐

Patient advised to inform DVLA ☐

Patient advised to inform insurance company ☐

DVLA Form

Alzheimers Org - Driving & Dementia

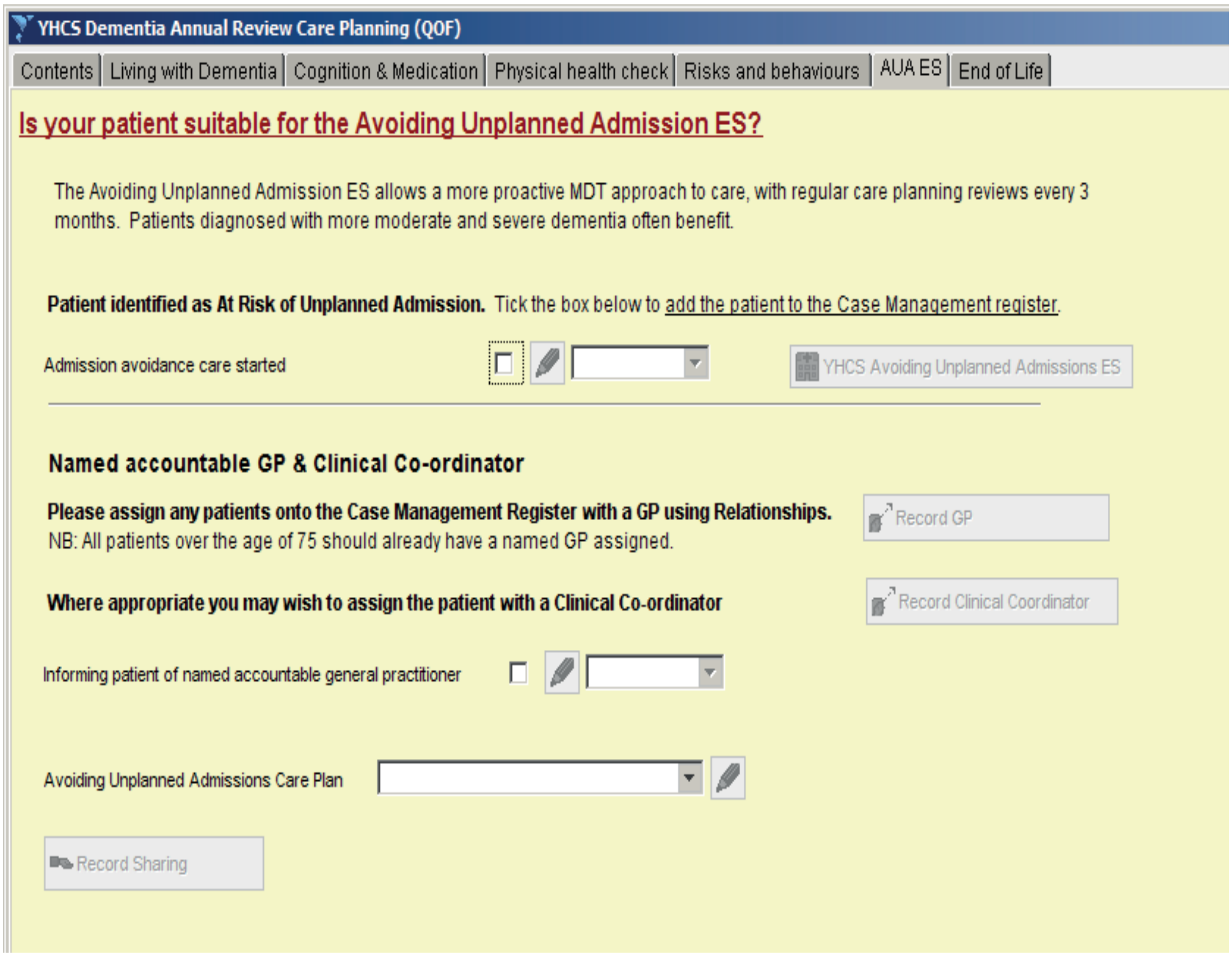
Risks

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



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 ☐

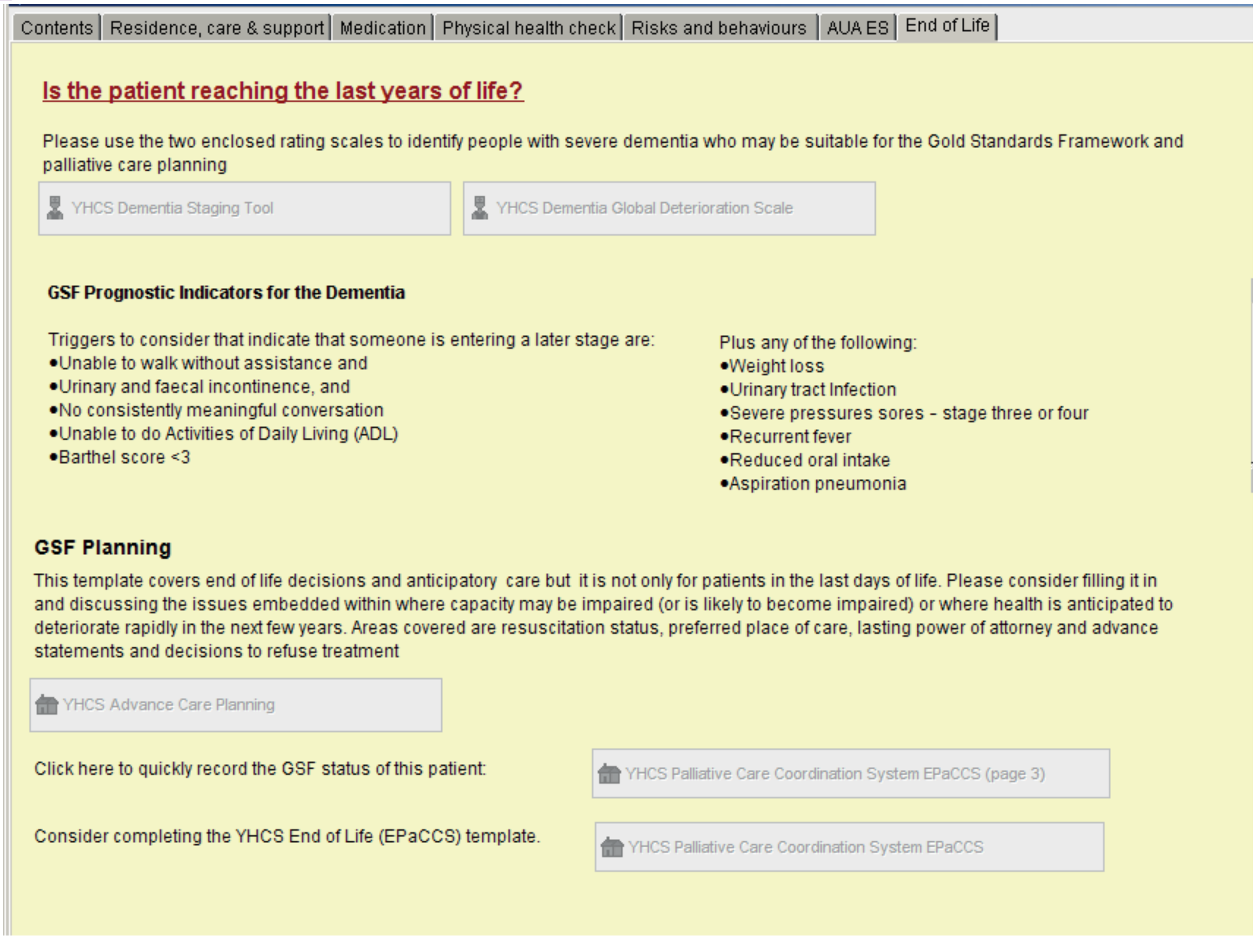
Named accountable GP & Clinical Co-ordinator

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.

Where appropriate you may wish to assign the patient with a Clinical Co-ordinator

Informing patient of named accountable general practitioner ☐

Avoiding Unplanned Admissions Care Plan



Is the patient reaching the last years of life?

Please use the two enclosed rating scales to identify people with severe dementia who may be suitable for the Gold Standards Framework and palliative care planning

GSF Prognostic Indicators for the Dementia

Triggers to consider that indicate that someone is entering a later stage are:
- 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

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 but 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 be impaired (or is likely to become impaired) or where health is anticipated to deteriorate rapidly in the next few years. Areas covered are resuscitation status, preferred place of care, lasting power of attorney and advance statements and decisions to refuse treatment

Click here to quickly record the GSF status of this patient:

Consider completing the YHCS End of Life (EPaCCS) template.

NHS
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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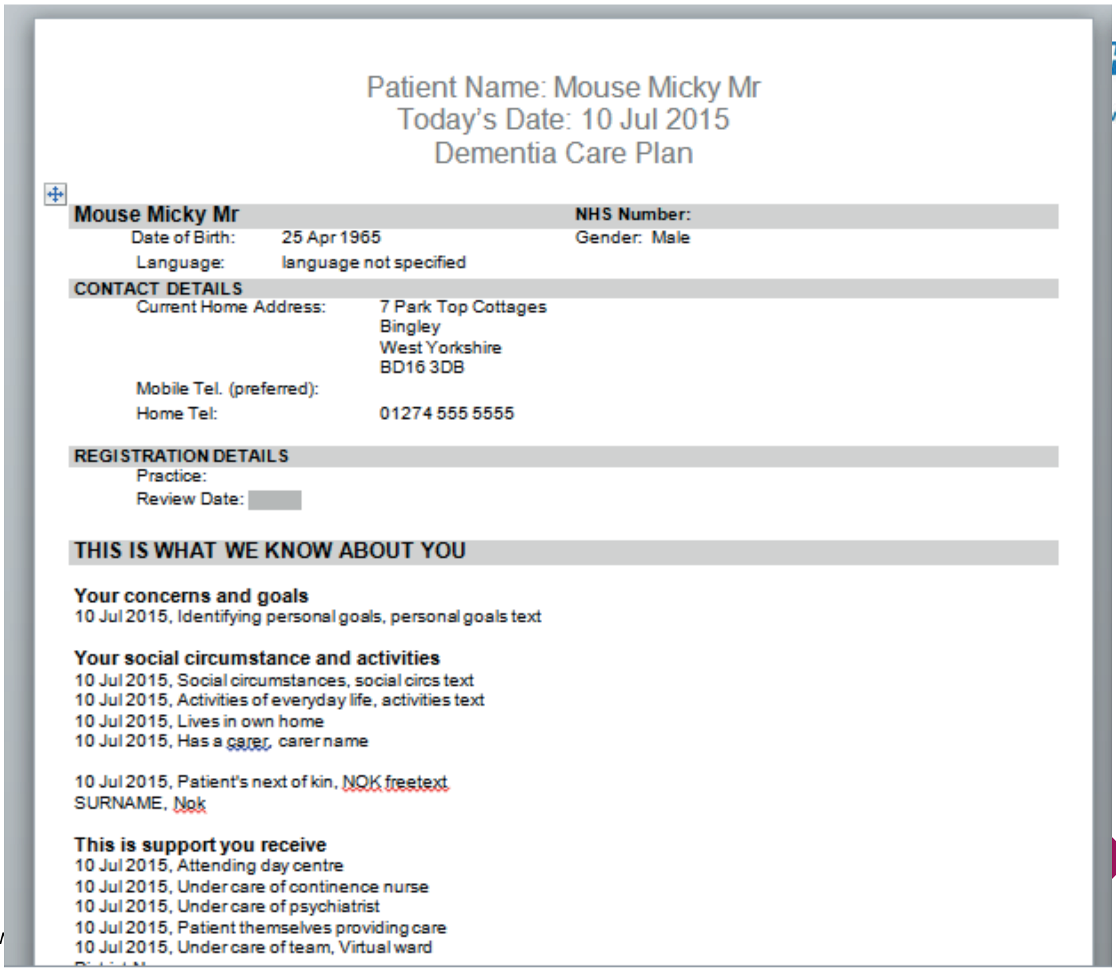


Patient Name: Mouse Micky Mr
Today's Date: 10 Jul 2015
Dementia Care Plan

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
West Yorkshire
BD16 3DB

Mobile Tel. (preferred):
Home Tel: 01274 555 5555

REGISTRATION DETAILS

Practice:
Review Date:

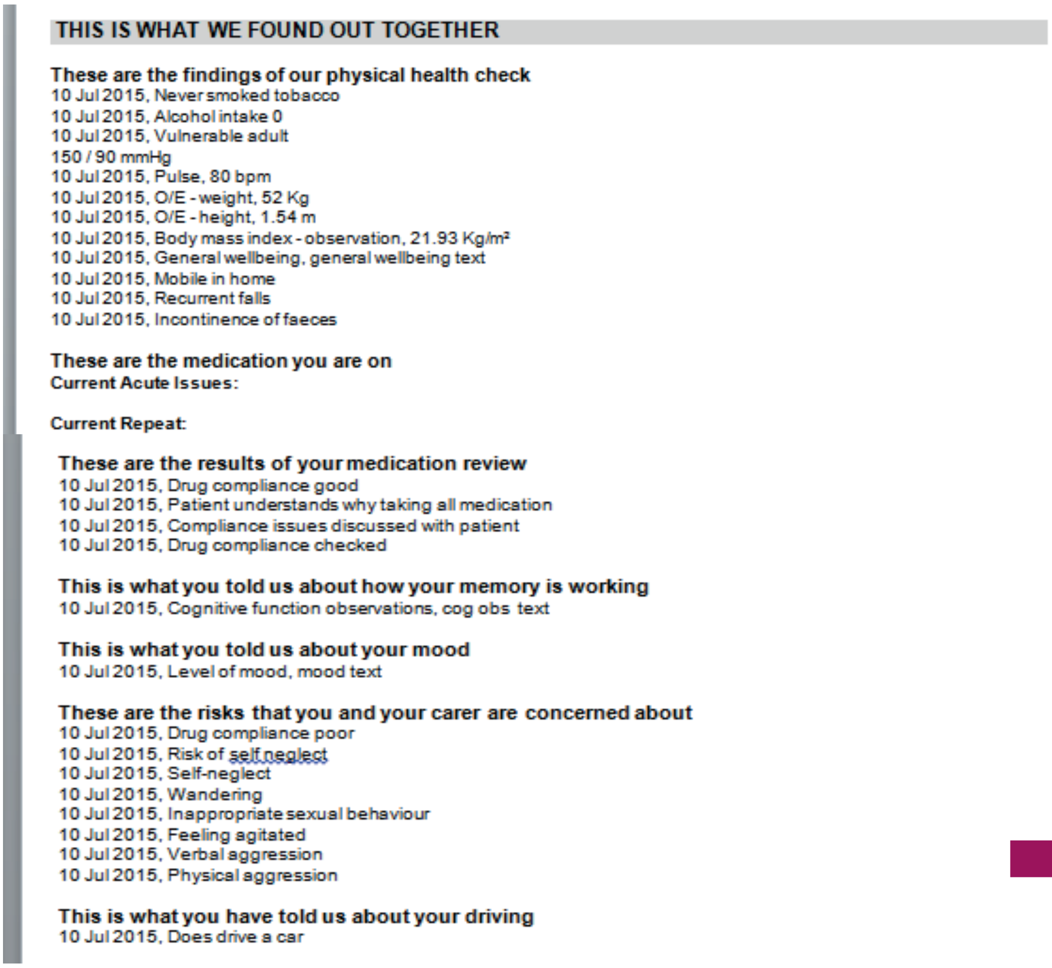
THIS IS WHAT WE KNOW ABOUT YOU

Your concerns and goals
10 Jul 2015, Identifying personal goals, personal goals text

Your social circumstance and activities
10 Jul 2015, Social circumstances, social circs text
10 Jul 2015, Activities of everyday life, activities text
10 Jul 2015, Lives in own home
10 Jul 2015, Has a carer, carer name

10 Jul 2015, Patient's next of kin, NOK freetext
SURNAME, Nok

This is support you receive
10 Jul 2015, Attending day centre
10 Jul 2015, Under care of continence nurse
10 Jul 2015, Under care of psychiatrist
10 Jul 2015, Patient themselves providing care
10 Jul 2015, Under care of team, Virtual ward



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, Pulse, 80 bpm
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, General wellbeing, general wellbeing text
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:

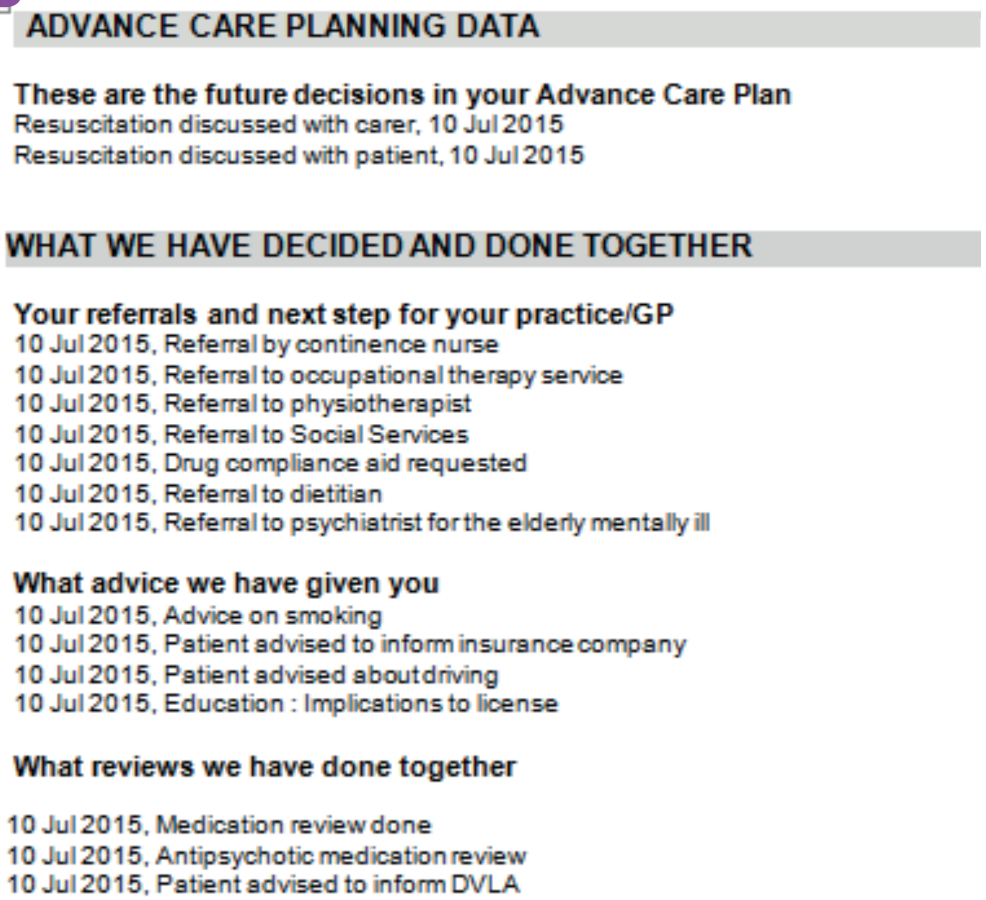
These are the results of your medication review
10 Jul 2015, Drug compliance good
10 Jul 2015, Patient understands why taking all medication
10 Jul 2015, Compliance issues discussed with patient
10 Jul 2015, Drug compliance checked

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 self neglect
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



ADVANCE CARE PLANNING DATA

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

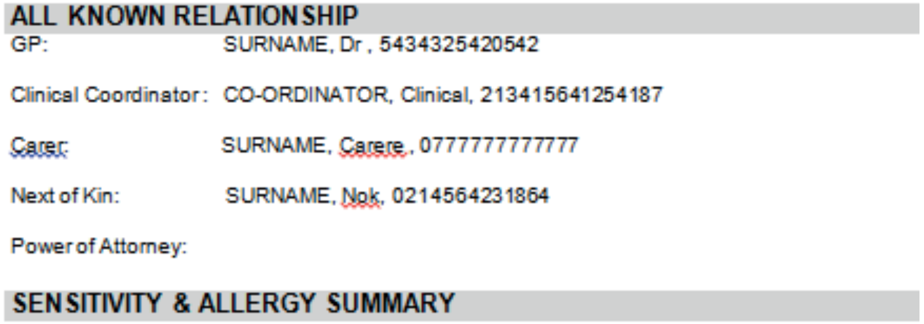
WHAT WE HAVE DECIDED AND DONE TOGETHER

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 RELATIONSHIP

GP: SURNAME, Dr , 5434325420542

Clinical Coordinator : CO-ORDINATOR, Clinical, 213415641254187

Carer: SURNAME, Carere , 077777777777

Next of Kin: SURNAME, Nok, 0214564231864

Power of Attorney:

SENSITIVITY & ALLERGY SUMMARY

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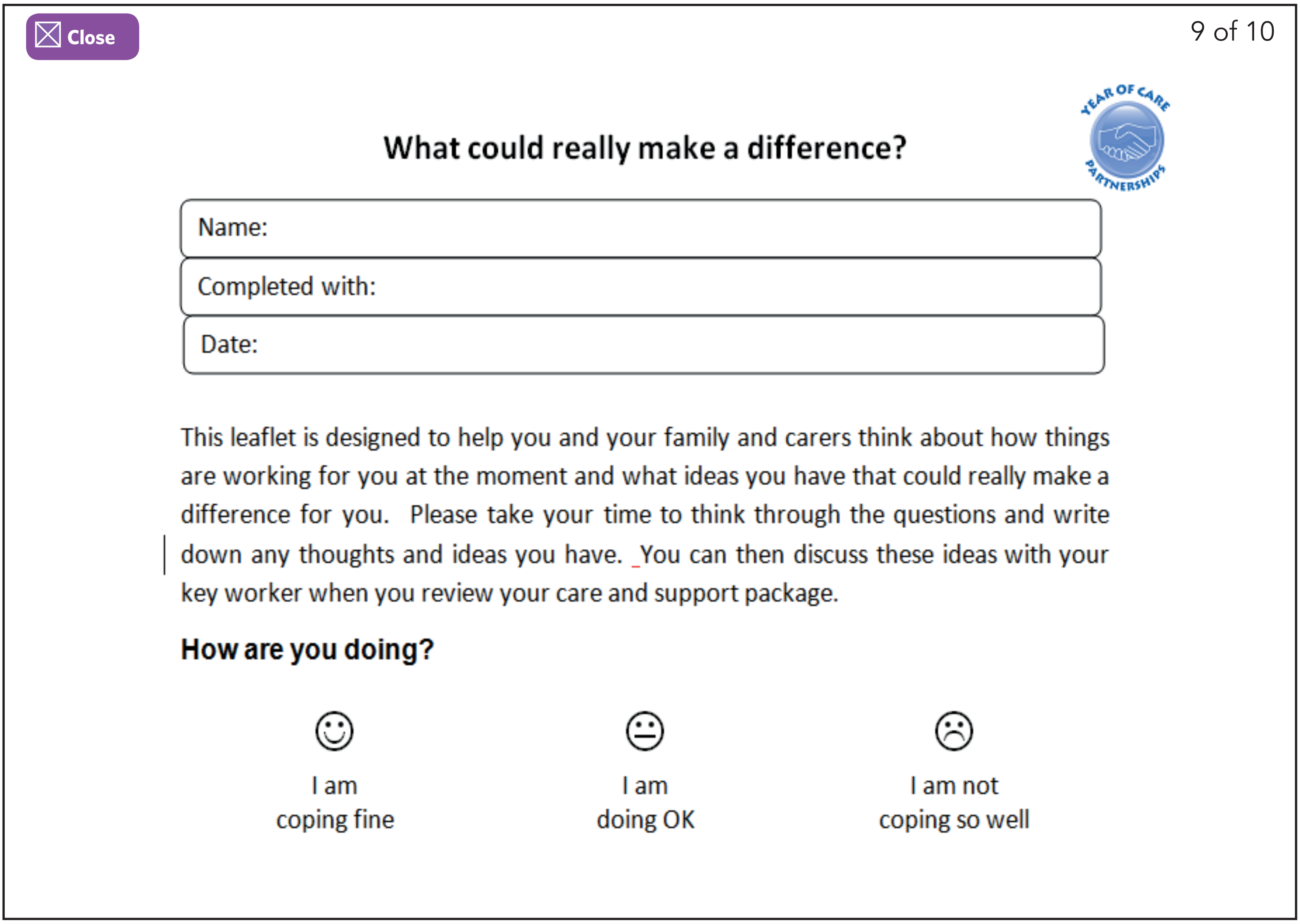
Close



What could really make a difference?

Name:

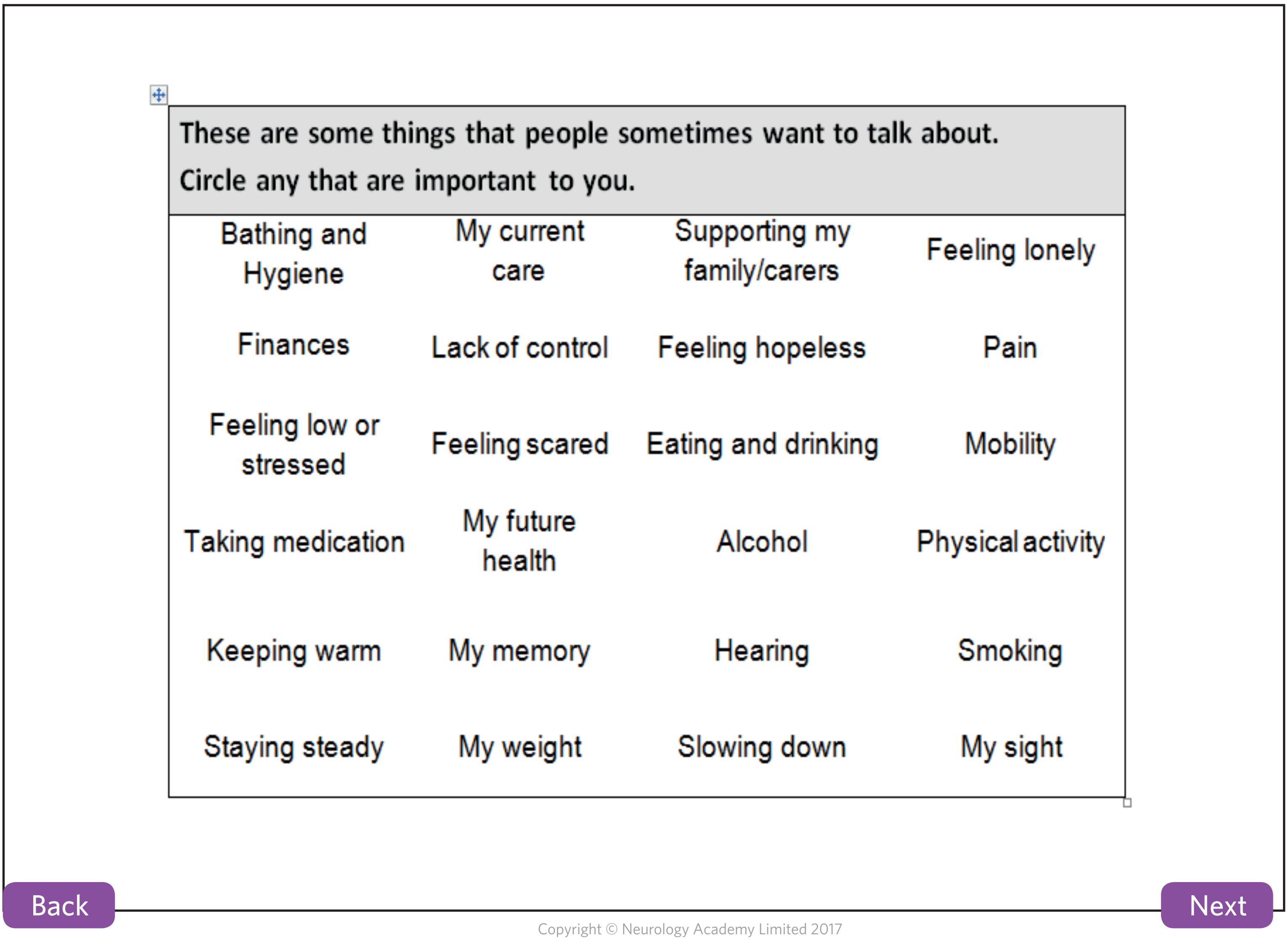
Completed with:

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?

☺	😐	☹
I am coping fine	I am doing OK	I am not coping so well

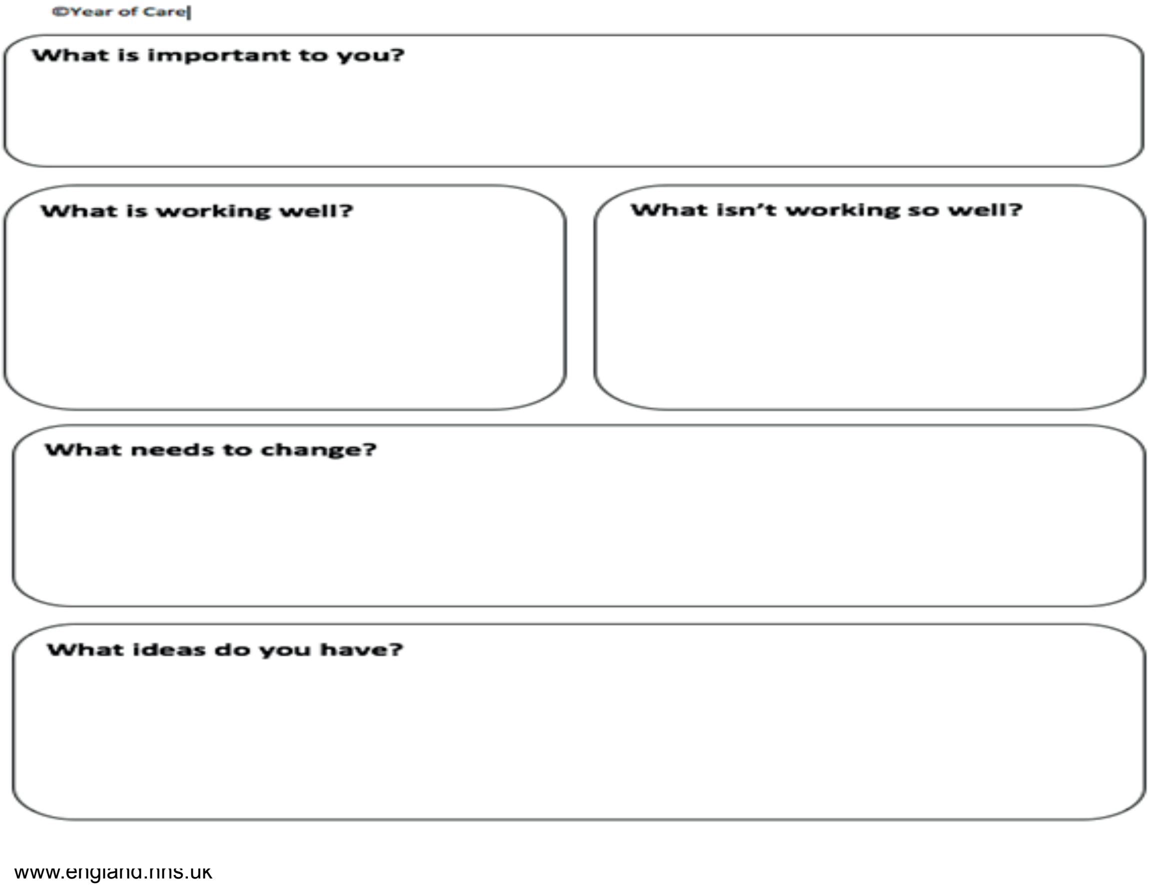


These are some things that people sometimes want to talk about. Circle any that are important to you.

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

Back

Next



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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☒ Close

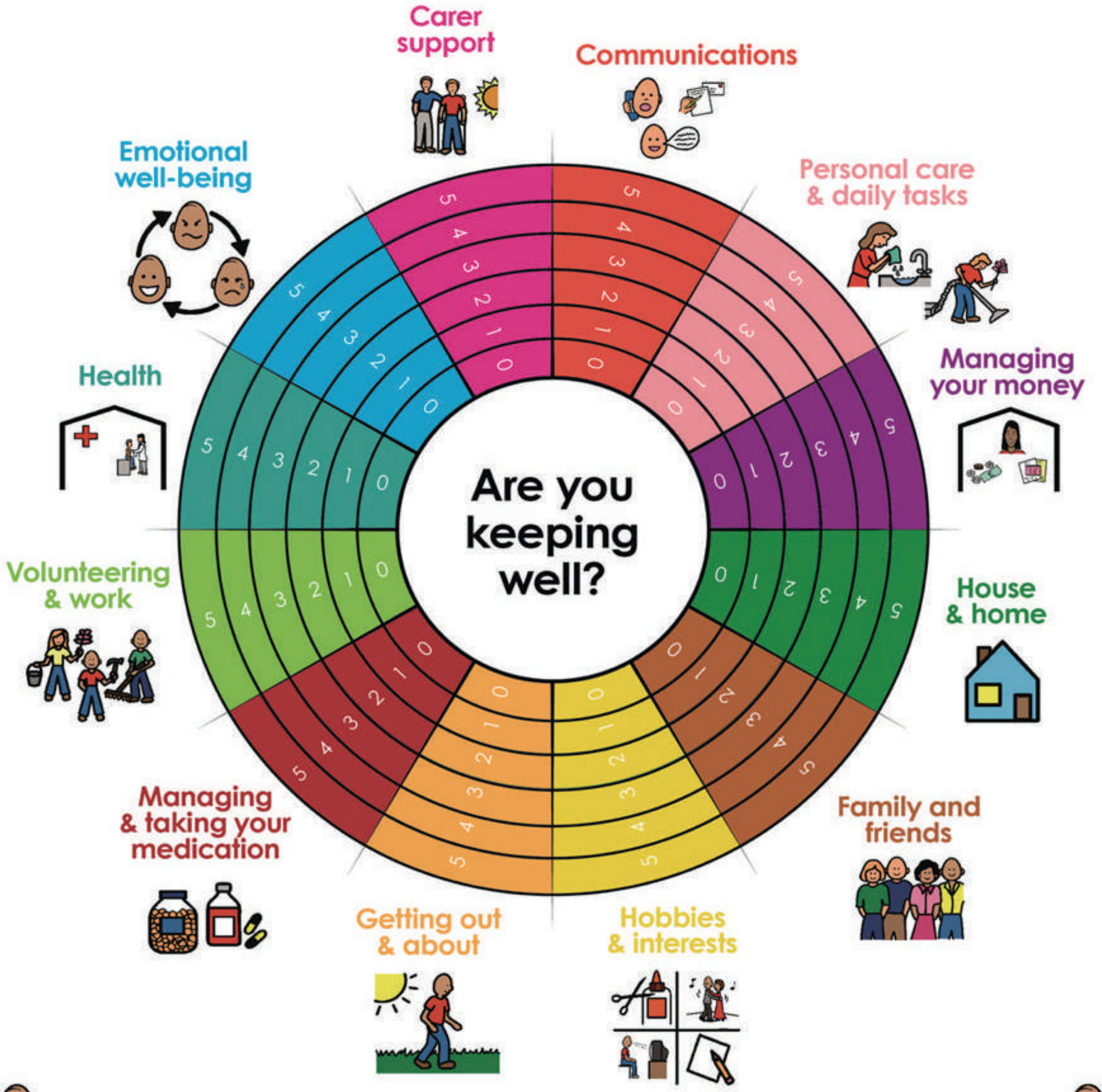
StayingWell
thinking today for tomorrow

Bolton Council

NHS
Bolton Clinical Commissioning Group

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.



Are you keeping well?

Carer support

Communications

Personal care & daily tasks

Managing your money

House & home

Family and friends

Hobbies & interests

Getting out & about

Managing & taking your medication

Volunteering & work

Health

Emotional well-being

0	1	2	3	4	5
I am very unhappy. This is a big concern.	I am unhappy, this is on my mind.	I am not unhappy, but there are some aspects that slightly concern or niggle me.	I've not really thought about this, it's fine.	I am happy with this.	I am very happy, this is one of the best parts of my life.

Scoring of 0-2 will need a further detailed conversation to identify appropriate information, advice and support

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