Dementia Academy®

The Brain Health Clinic blueprint

3 in 10 people's dementia might be preventable

'A Brain Health Clinic blueprint to detect and manage early-stage cognitive decline: consensus guidance'

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Version 2.

User note: Each tab at the bottom of the page will take you to the start of that section, except the ‘Resources’ tabs; each ‘resources’ tab will take you to the relevant page of references for that section.

Our vision: the Brain Health Clinic blueprint

Over 30% of all dementia is preventable by reducing many of the health and lifestyle risks we already understand.

This includes **vascular risk factors** like obesity, diabetes, high blood pressure, smoking, and alcohol misuse.

It also includes **lesser-known risk factors** like inactive lifestyles, loneliness, later-age depression, mid-life hearing impairment, and less common risks like head-injury and delirium.

3 in 10 people's dementia might be preventable

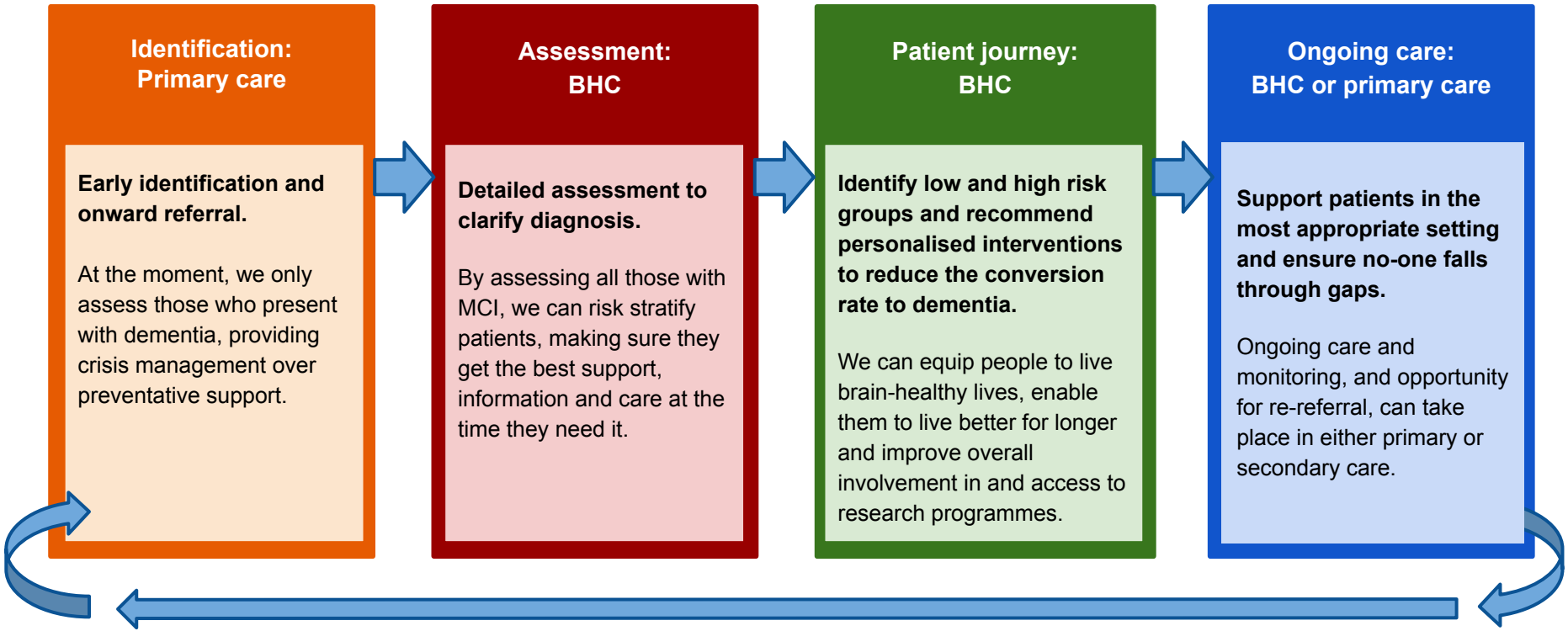
This blueprint for a Brain Health Clinic (BHC) sets out a vision for managing early cognitive decline using a prevention approach, maximising brain health and quality of life for the person with the concern and their families.

At the moment, people diagnosed with early cognitive decline who may be in the pre-dementia stage, are generally referred back to primary care **without intervention**, to wait for dementia to emerge before action is taken.

Using existing resources, and reconfiguring the way current services are provided, the BHC model aims to support people with early cognitive impairment to remain well for longer, changing outcomes, and potentially preventing up to 3 in 10 people developing dementia.

This document sets out the key components of a BHC preventative model which may be adapted to any region and their needs.

Your Brain Health Clinic blueprint



Resources

Use existing services and roles in new ways so that you can better support individuals, improve the health of your overall community, and prevent up to 30% of people from developing dementia. These resources outline and signpost to help you.

Identification of appropriate referrals - why is it important?

Early cognitive decline, including mild cognitive impairment (MCI) refers to a condition in which someone has minor problems with cognition which are worse than would normally be expected for a healthy person of their age but not severe enough to interfere significantly with daily life.

- **One-third** of the population aged over 60 years is thought to have **MCI** and
- **6-15%** of these people **will develop dementia** each year.
- Diagnosis of early cognitive decline, MCI or very early stage dementia in Memory Assessment Services is often inconsistent and intervention is minimal.

Before BHC

- Discharged to community
- Wait to see if dementia develops ☹

Patient presents in primary care with signs of early cognitive decline

Referral to MAS

After BHC

- Supported by BHC
- Equipped with preventative measures ☺

Identification of appropriate referrals (GP & MAS)

Primary care:

Patient presents with complaints of memory impairment.

GP undertakes a work-up to rule out

- psychological complaints including depression
- other non-primary memory problems e.g. alcohol and drug use
- reversible causes of cognitive complaints (e.g. thyroid dysfunction, vitamin B12 and folate deficiency)
- GPCOG or 6-CIT may be helpful
- lifestyle assessment

Memory Assessment Service (MAS) / similar:

Further clinical assessment
Includes: initial medical, cognitive and psychiatric assessment. It forms the basis of the referral to the BHC.

Recommended tools in clinical assessment to distinguish MCI from both normal cognition and dementia:

1. Addenbrooke's Cognitive Evaluation-III
2. the Montreal Cognitive Assessment. (initial assessment only - cannot detect the sub-type of MCI).

Scores on cognitive tests for those with MCI are usually 1 to 1.5 standard deviations below age- and education- adjusted normative means. These should be considered guidelines, rather than firm cut-points.

Useful resources: Dementia primer & Older people's mental health primer and NICE guidance.

Brain Health Clinic:

Checklist:

1. Memory impairment confirmed without clear causality
2. Clinical assessment carried out and confirms further action is needed
3. Scores 0 to 0.5 on the Clinical Dementia Rating Scale (CDR), i.e. preclinical or prodromal dementia.

Assessment: ensuring sub-typing and prognosis of early stage cognitive decline (overview)

Primary care

- Clinical

⟺

Brain Health Clinic

- **Cognitive**
- **Behavioural**
- **Functional**
- **Biomarker detection** inc fluid, digital, neuroimaging, genotyping

For information on how to set up a Brain Health Clinic using existing resources, ideas for a business case, and suggested roles and responsibilities of the multidisciplinary team involved, go to Resources.

Assessment: ensuring sub-typing and prognosis of early stage cognitive decline

(Initial assessment: Global cognitive evaluation across different cognitive domains. Carried out at clinical assessment.)

Further assessment if MCI detected to striate into risk categories and ascertain if higher risk for progression to dementia due to Alzheimer disease: A feasible neuropsychological battery may be:

- The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS)
- The Free and Cued Selective Reminding Test (FCSRT) especially beneficial in computerised form on a tablet/ laptop.
- The Cambridge Neuropsychological Test Automated Battery (CANTAB, Cambridge Cognition) - a tablet-based cognitive test battery that captures the domains of attention, episodic memory, processing speed, working memory and executive function

Note: There is no agreed protocol; this recommendation is based on: protocol from Prevention of Alzheimer's Disease (EPAD) study 4, the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS), the NIH EXAMINER/Toolbox 5 and additional tests of reaction time, processing speed, conceptual shifting, selective attention, allocentric spatial memory, paired-associate learning and navigation in egocentric space.

Assessment: ensuring sub-typing and prognosis of early stage cognitive decline (overview)

Those with MCI and very early stage dementia have significantly higher behavioural and psychological symptoms (BPS) than the general populace. Depression and apathy are most commonly reported and can indicate future decline into dementia. Forms of BPS such as agitation, anxiety, apathy, delusions, depression, disinhibition, and irritability are significantly more common in those with MCI.

Assessment of BPS in MCI can be carried out with the Neuropsychiatric Inventory which has different versions:

- informant-rated versions (NPI-12) and (NPI -Q)
- clinician-rated version, which may be an option if attendees do not bring informants to clinic.

Other useful assessment tools include the Mild Behavioural Impairment Checklist (MBI-C) and the Amsterdam Instrumental Activities of Daily Living Questionnaire (A-IADL-Q).

Assessment: ensuring sub-typing and prognosis of early stage cognitive decline

Functional ability refers to an individual's capacity to complete the everyday tasks necessary for independent living. It is usually divided into 'basic activities of daily living' (BADL), e.g. feeding and toileting, and more complex 'instrumental activities of daily living' (IADL), e.g. managing finances and taking medication 2.

- Traditionally, the definition of 'MCI' required functional ability to be intact, but the recent criteria for MCI due to AD recognize the presence of subtle problems performing complex functional tasks 3 .
- Difficulties performing IADL in MCI can be predictive of subsequent dementia 4,5 so assessing subtle change in IADL may provide vital information at the preclinical and prodromal stage of AD to support an early diagnosis.

Many assessment tools are now out of date in relation to the changes in technology and societal activities which dictate day to day life. The recommended assessment tools which address theses changes are:

- The Amsterdam IADL Questionnaire (A-IADL-Q). A shortened, 30-item version (A-IADL-Q-SV), is now developed and correlates highly with the original version 6
- Functional Activities Questionnaire (FAQ) 7

Assessment: ensuring sub-typing and prognosis of early stage cognitive decline

Neuroimaging and fluid biomarkers are necessary to accurately identify people with MCI in particular, identifiable diagnosis such as AD, and those at risk of progressing to dementia for another non-AD cause.

Of those with biomarker positive amnestic MCI, about 40% will progress to mild AD within two years (Korolev 2016). While other biomarkers (i.e. urine, plasma, saliva) and genotyping (i.e. Apo lipoprotein E status) are not currently used clinically for risk stratification of AD, these may become available in the future.

- Neuroimaging (i.e. MRI, CT, FDG-PET, amyloid and tau PET, DAT)
- Fluid (i.e.cerebrospinal fluid) - studies have suggested that levels of biomarkers in the cerebrospinal fluid (e.g. Aβ 42 and tau protein) may help identify patients with MCI who are more likely to progress to AD, routine lumbar puncture is not generally recommended for clinical evaluation.
- Digital - New ways of capturing continuous measures of change in the daily course of life (e.g. activity levels, gait and sleep) are becoming a focus of interest in clinical settings (Cygnus) and may, through generating functional 'real world' bio-signatures, help indicate if a patient is on a trajectory towards dementia. 'Wearables' like activity watches and programmes like Sea Hero Quest (a game which tests spatial navigation and orientation) using smart devices, smartphones, tablets and computers also gather data in new ways and give people more control over their own data.
- Genotyping - Although this is not done routinely, the presence of an APOE e4 allele may modestly increase the risk of progressing from MCI to AD dementia.

BHC patient journey (overview)

Identification → Assessment → BHC: patient flow

Stream A: research
Intervention 1

Research complete

Stream B: low / moderate risk
Intervention 1 and 2

Stream C: high risk
Intervention 1, 2 and 3

Ongoing care

Monitoring under primary care

Monitoring under BHC

Interventions:

1. Risk factor modification and managing co-morbidity
2. non-pharmacologic cognition-based interventions
3. Disease-modifying therapy (have in readiness)

Patient journey: risk stream

BHC: patient flow

Stream A: research
Intervention 1

Stream B: low / moderate risk
Intervention 1 and 2

Stream C: high risk
Intervention 1, 2 and 3

Interventions: 1. Risk factor modification and managing co-morbidity / 2. Non-pharmacologic cognition-based treatment / 3. Disease-modifying therapy

Intervention 1. Patients will be connected with various current research trials for which they meet the profile. See ongoing care and identify which areas are appropriate to address with the individual, so far as they will not impact on the research programme's stipulations.

Interventions 1 & 2. Patients have low risk of transitioning to dementia in the short term. Offer individual goal planning sessions with specialist nurse for post-diagnostic information, dementia prevention strategies and advice. Signpost, or enable access to services as jointly identified to support agreed goal plan.

Interventions 1, 2 & 3. Patients have higher risk of transition to dementia in the shorter term. Recall for testing at 9-12 month intervals (max two recall tests). If recall tests suggest transition to dementia refer to MAS consultant for diagnosis and commencement of treatment where indicated and access to dementia services.

Enablers

The Join Dementia research website: https://www.joindementiaresearch.nihr.ac.uk/

Shared patient records, good communication between BHC and primary care, scoping of local services to aid referral, information or self-directed care, use of existing GP-held dementia records

Shared patient records, good communication between BHC and primary care, clinical database for scheduled follow up and monitoring.

Ongoing care

Onward patient journey including monitoring, referral to appropriate services, discussions and re-assessment for BHC will take place in primary care for those in Stream A and B, and in the BHC for those in Stream C.

Identification | Assessment | Patient journey | Ongoing care | Resources

Management and patient flow: intervention 1

Intervention model 1: risk factor modification and managing co-morbidity

Known risk factors for dementia, many of which also overlap with stroke, cardiovascular disease and type 2 diabetes include:

- social isolation or loneliness
- mid-life hearing loss
- physical inactivity or sedentarism
- not receiving early support for depression
- alcohol misuse
- vascular risk factors
- Quality of sleep

By taking steps to help patients address the areas of their life which might be putting them at risk of health problems now or in the future.

Vascular risk factors are also key areas to address - promoting ideal cardiovascular health for our under 65's with MCI is the most evidenced based intervention we can currently deliver (Sabia et al 2019).

Primary care is uniquely placed to coordinate risk factor modification and monitor progression. This might include medicine management and social prescribing, as well as tools, services, advice and signposting.

Useful examples

There are lots of different ways that we can try to mitigate against these risk factors, such as:

- Positive cardiovascular health, particularly in 30-50 year olds, can be a significant preventative for MCI (outlined in the BMJ)
- lifestyle and dietary advice (like in the HATICE study),
- use of hearing aids in middle years which can reduce brain aging by up to 8 years (PROTECT study)
- lifestyle coaching or programmes (such as the HOPE programme or Be Well),
- social prescribing or linking with voluntary roles (like Altogether Better)
- movement support through information, classes, or local initiatives like Park Runs.
- digital solutions, from conditions management tools like DAFNE to basic blood pressure monitors and pedometers (the FINGER study)
- signposting to books and podcasts, and social networks supporting lifestyle change
- offering lifestyle and wellness clinics (like in Torbay)

Management and patient flow: intervention 2

Intervention model 2: non-pharmacologic cognition-based interventions

There is evidence that non pharmacological interventions can improve cognitive functioning of those with MCI and impact on those lifestyle factors known to increase risk of developing dementia.

A Cochrane review of cognition-based interventions found that patients with MCI demonstrated significant improvement in immediate and delayed verbal recall with cognitive training but found there was little evidence for memory interventions.

Evidence is inconclusive at present for preventing dementia through computerised cognitive training but some studies have found that cognitive training can improve some aspects of memory and thinking, particularly for people who are middle-aged or older, whilst early evidence suggests that brain training may help older people to manage their daily tasks better.

There is clearly much more research needed in this area, yet Alzheimer's Society note 'use it or lose it' in their advocation of an active brain being a healthier brain.

Useful examples

There are lots of different tools and technologies that can assist with brain training. These include:

- Each individual can find something that challenges their brain and that they really enjoy, to do regularly. For example:
  - study for a qualification or course, or just for fun
  - learn a new language
  - do puzzles, crosswords, number challenges or quizzes
  - play card games or board games
  - read challenging books or write (fiction or non-fiction).
- Talking and communicating with other people and creating or maintaining connections with loved ones
- Volunteering, or joining a club or community group to keep socially active

Management and patient flow: intervention 3

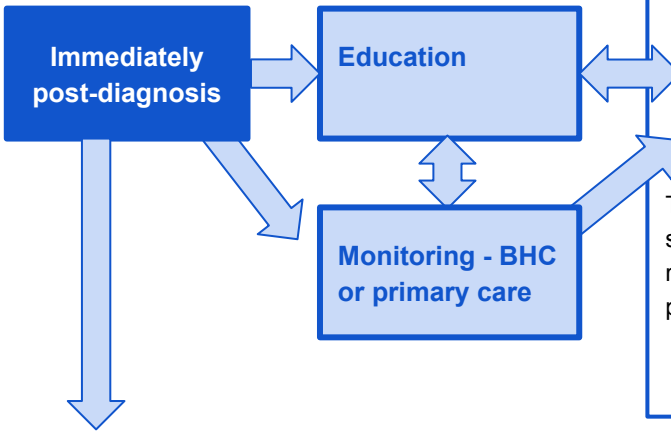
Intervention model 3: disease-modifying therapies

This form of treatment is not available for dementia patients yet, but preparing services and agreeing a clear patient journey is vital to make sure those who need to can access the treatment quickly once it is.

'The Edinburgh Consensus: preparing for the advent of disease-modifying therapies for Alzheimer's disease' (2017) summarises:

- Since treatments are likely to be most effective in the early stages, identification of clinically relevant brain changes (for example, amyloid burden using imaging or cerebrospinal fluid biomarkers) will be crucial.
- While current biomarkers could be useful in identifying eligibility for new therapies, trial data are not available to aid decisions about stopping or continuing treatment in clinical practice. Therefore, effective monitoring of safety and effectiveness when these treatments are introduced into clinical practice will be necessary to inform wide-scale use.
- Equity of access is key but there is a tension between universal access for everyone with a diagnosis of Alzheimer's disease and specifying an eligible population most likely to respond. We propose the resources necessary for an optimal care pathway as well as the necessary education and training for primary and secondary care.

Ongoing care



Legal and ethical

Health

Physical considerations

Activities

These categories should be considered for all those identified as having early cognitive decline, regardless of stream. Every journey will be tailored according to the individuals' needs and people will need to access or re-access different elements at different times. Some elements are more suited to a person who has progressed to dementia, others are relevant for those with early cognitive decline, others for both.

(nb If on 'Stream A: Research' take into account any specific instructions as per their research involvement.)

Immediately post-diagnosis

1. Identify brain health guide and a first point of contact in crisis*
2. Add individual to GP register of those with early cognitive decline - establish new or add to existing dementia register
3. Establish shared records

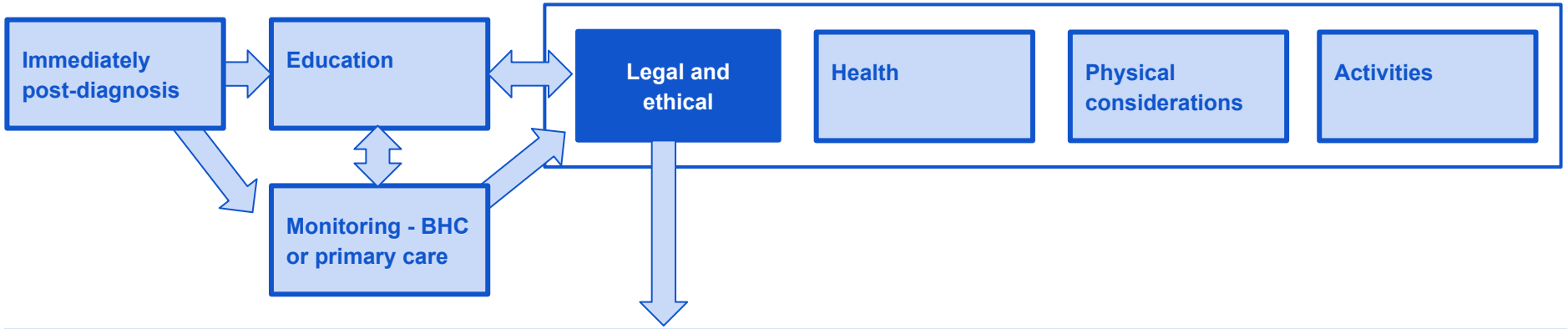
*This might be a specialist nurse for dementia or Parkinson's if appropriate, a consultant, someone in the BHC, or their GP, depending on the individual's needs and local service availability.

Ongoing care

Education

- Explain implication of diagnosis and give follow on information
- Offer counselling and support for the individual and family / carer to accept diagnosis
- Signpost / refer to reliable and valid information i.e. through locally available education programmes e.g. HOPE, Be Well
- Decision making underpinned by National Service Framework and NICE guidance
- Use of established and validated service user leaflets and online information such as from the voluntary sector and local services
- Use evidence based practice that is reliable and consistent

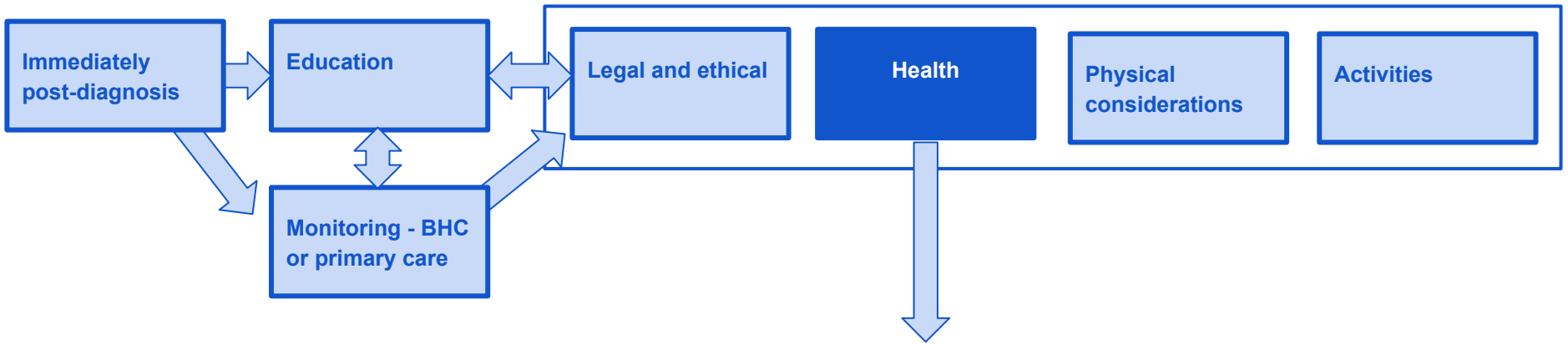
Ongoing care



Legal and ethical

- Determine capacity
- Consider individuals wishes and preferences regarding current and future care decisions
- Establish or discuss LPA health and finance
- Anticipatory care for e.g. partner/career becoming suddenly unwell or hospitalised
- Advanced care planning including preferred place of care both current and future
- Discussion around legalities of driving and additional assessments i.e. driving assessment centres, planning on retiring from driving

Ongoing care



Health

- Identified health profession team for individual needs including GP
- Person with early cognitive decline to have regular review meetings with team can be virtual provided keyworker has been in contact with person or family
- Medication management in view of dementia diagnosis
- Consider impact of comorbidities
- Annual review led by keyworker or as need demands
- Anticipatory care planning for acute illness i.e. UTI which could adversely affect confusion or behaviour

Ongoing care

Physical considerations

- Education and information about the benefits of movement in everyday life, and of exercise
- Identification of movement and / or exercise that would be beneficial, enjoyable and within capabilities
- Information regarding access to groups i.e. NERS
- Recognition and management of challenging behaviours that may impact on ability to engage

Ongoing care

Activities

- Support to continue with current activities hobbies and clubs
- Information about dementia friendly activities in local area
- Utilise day hospitals or day centres
- Directory of both private and council led activity centres
- Engagement with U3A
- Social prescribing to reduce risk of social isolation including dementia-friendly swimming, walking groups, men's sheds

Ongoing care

BHC (Stream C patients)

Tailor follow-up requirements to each patient's needs. Consider the following as a checklist' to help assess those requirements:

- Assess potential for reversal
- Assess the rate of progression
- Are there behavioural symptoms?
- Is there adequate social support?
- When available initiate new treatments

At follow ups, consider all monitoring listed for Stream A & B, as well as:

- Carer burden and risk of mood disorder
- Encouragement of discussions about living and dying well with dementia and anticipate palliative care needs, referral to 'Dying Matters' (NCPC) or local initiatives.

Primary care (Stream A and B)

Primary care level monitoring checklists / guidance for MCI and cognitive decline.

- ANNUAL MoCA OR other COG ASSESS if patient reports noticing cognitive decline or if, by comparison to the previous year's notes, the individual seems to be demonstrating decline
- If there are concerns that the patient is experiencing cognitive decline, return to start of pathway for potential referral to MAS or back into BHC
- Blood tests for reversible causes, e,g, B12, iron, thyroid, diabetes
- Blood tests for cardiovascular health screening fasting glucose and cholesterol

Return to any relevant lifestyle discussions previously considered:

- Offer encouragement, support, signposting or local referral where possible
- Request feedback on lifestyle changes undertaken to encourage wellness dialogue
- Optimise vascular risk factors, e.g. signpost to smoking cessation
- Encourage hearing aid use and social engagement
- Consider referral / opportunities for social prescribing

Resources Useful information to give to patients and their families

Information for patients - printable

The local library is a hub of all available information on local resources, groups and wider information

Information on voluntary organisations which might be useful:

- Alzheimer's Society – www.alzheimers.org.uk
- Dementia UK – www.dementiauk.org
- Admiral Nurses – www.dementiauk.org/admirialnurse
- Crossroads – local websites eg – www.crossroadsbridgend.org.uk
- Royal British Legion – www.britishlegion.org.uk
- Red Cross – www.redcross.org.uk

Please insert information for patient e.g. details of keyworker, note on local groups, community projects and other useful information:

Information for patients - signpost according to locality

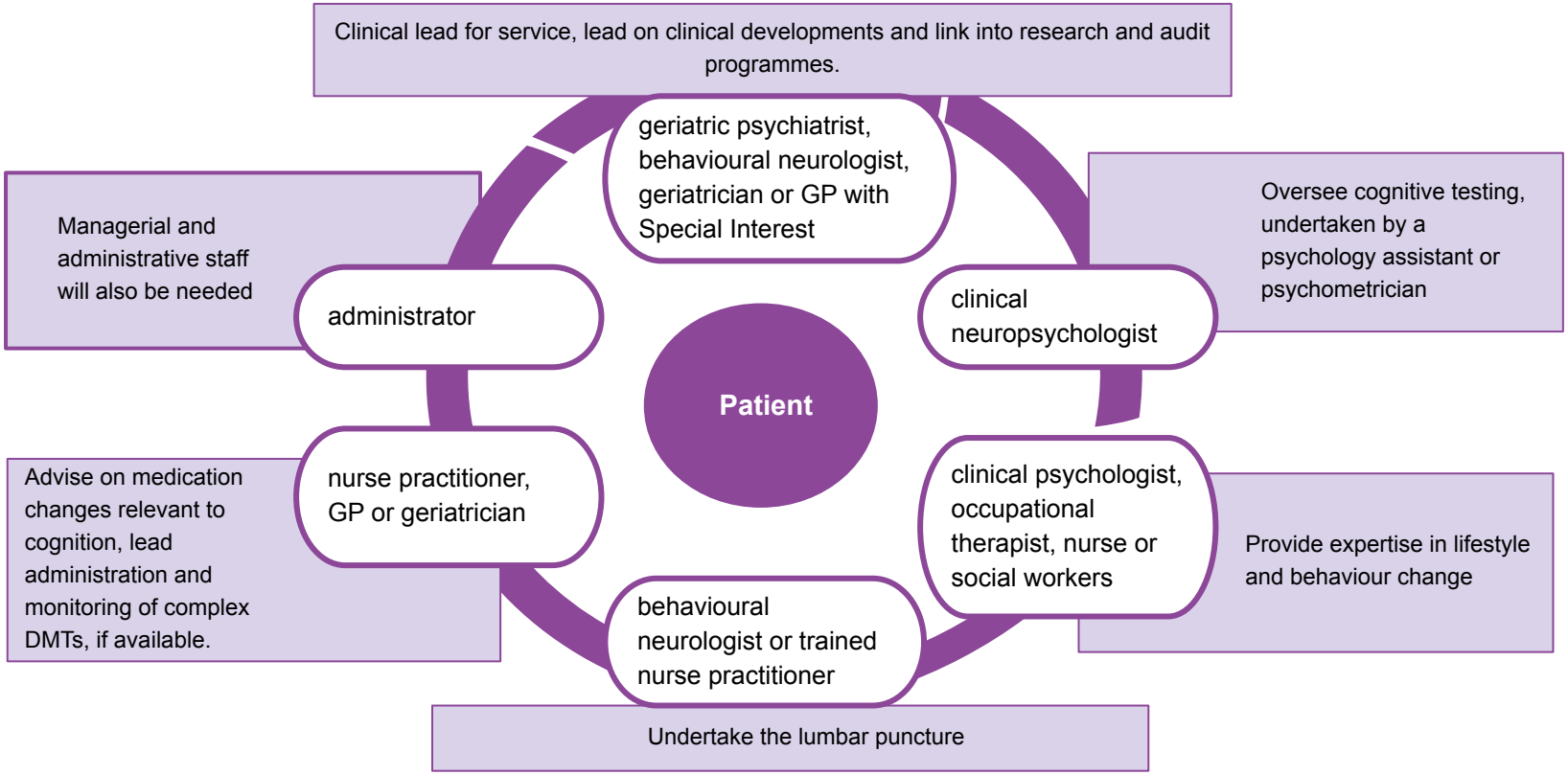
Local groups which may be available

- Dementia café's (mild to moderate)
- Memory lane café's (moderate to advanced)
- Friendship groups
- Dementia friendly swimming groups
- Dementia friendly exercise classes
- Choir
- Gardening co-op or group
- Walking groups, park runs or other movement and community-related activities
- Mindfulness course for both patient and carer
- Carer support and education

If individual has dementia, then as it progresses, signpost to:

- Support via social services specifically for dementia
- To support with personal care, meals, befriending, medication prompting management

Resources: An example of roles and responsibilities in a BHC multidisciplinary team



BHC multidisciplinary team and lead

The core team of a successful BHC will be multidisciplinary.

An individual with expertise in dementia care will act as clinical lead. They will:

- ensure clinical oversight of the service,
- act as a link across disciplines,
- lead on clinical developments and
- link with research and audit programmes.

This role might be performed by a geriatric psychiatrist, behavioural neurologist, geriatrician or GP with special interest

See BHC MDT figure.

Utilise existing resources

BHCs could be supported by various services already available in most local health economies, such as wellbeing or ‘healthy living’ groups. This will reduce overlap in intervention for patients and encourage social interaction.

- High Intensity Primary Care teams can give short term intensive care to particularly high risk patients.
- Expert patient programmes
- DESMOND education groups for diabetes provide further opportunity.
- HOPE programme

Optimal service setting: BHC main

A BHC would ideally be coordinated from a primary care setting, if specialised pharmacological interventions (i.e. DMTs) were not involved.

For services with existing dementia-focussed Memory Assessment Clinics (MAS), a BHC could be an extension of the MAS, enabling seamless referral in either direction. (See business case ideas).

Optimal service setting: DMTs (intervention 3)

Access to acute care facilities (i.e. for infusion and post-infusion monitoring) may be required.

Utilise existing resources (DMTs)

The latter already exist for dermatology, rheumatology and some neurology clinics that offer treatment and monitoring of ‘biological therapies’, often in day-hospital settings.

Population management and preventative care

The National Audit for Dementia state that there are 850,000 people living with dementia in the UK. This is expected to rise to one million by 2025 and continue to increase to two million by 2051 (NAD 2019). That's 150,000 more people living with dementia in 6 years.

- If around 30% of dementia is preventable, BHCs, or similar preventative services, **could reduce that number by 500**. That's 500 people in the UK who won't be living with dementia in 6 years' time. If they receive preventative care now.
- In the next 38 years based on the NAD's data, that is **3,795** people who could be prevented from living with dementia.

No new commissioning - but repurposing of existing resources

Rather than adding additional clinics into a team's workload, what about changing the focus or purpose of an existing clinic session? Could you repurpose an existing multidisciplinary clinic? If not, is there an MDT clinic, either acute or community-based, that could be informally partnered with your clinic for referral or input.

Changes can be small. Rather than taking away from existing services, it is instead looking at the same existing population's needs from a different perspective - and will improve patient outcomes and reduce the future demand on dementia-specific services.

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Resources

Queries, more information and support

Thank you for using this resource. It is in its first iteration and we are keen to make it as usable as possible. If you have any suggestions on how to make the blueprint easier to use, or information you would find helpful in it, please get in touch.

If you have any comments, queries, or wish to get in touch with one of the professionals in the consensus group which developed the blueprint, please contact Dementia Academy, part of Neurology Academy.

The article supporting the background and method to the blueprint is:

'A Brain Health Clinic blueprint to detect and manage early cognitive decline: consensus guidance' (awaiting publication)

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