Report for: Adults and Health Scrutiny Panel – 17th November 2022

Title: Update on Living Well with Dementia in Haringey

Report authorised by: Beverley Tarka, Director of Adults, Health and Communities

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Ward(s) affected: All

Report for Key / Non Key Decision: Non Key Decision

1. Describe the issue under consideration

1.1 This paper outlines our approach to Living Well with Dementia, which forms an important section of Haringey's joint and multi-agency Ageing Well Strategy and our progress towards progressing this section and plans for improvement over the next year or so.

1.2 The overall aim multi-agency Council, NHS and voluntary sector partners agreed as part of the Age Well Board is to ensure people with dementia are diagnosed as early as possible and that they and their carers get the right treatment, care and support for them that will help them live as long, fulfilling and healthy lives as possible as they age.

1.3 We set out this report to recognise that whilst we have made some improvements in the support that is available, partners recognise there is a need to improve these statutory services and to bring solutions together in a way that feels like a more coordinated and holistic approach to the response people with lived experience of the condition tell us is needed.

1.4 Partners – the Council and NHS working with partners such as the voluntary sector - are currently implementing a plan of support that is guided by these groups, notably the Dementia Reference Group, and this includes 'getting the basics right' following the delays to progress against plans caused by the pandemic in some services. Some of the solutions relate to mobilising the community to develop a 'dementia-friendly Haringey' – small things can make a big difference to people's lives, and this can simply be about mainstream services we all use becoming more 'dementia-friendly'.

1.5 We are asking the Panel to note the contents of this report, endorse our approach and to help us identify community-based opportunities to connect things together or for future development.

2. Background information

2.1 Dementia is a term describing a collection of conditions, such as Alzheimer's Disease or vascular dementia, associated with the brain. These conditions affect individual's memory, ability to undertake everyday tasks, communication,

problem-solving and perception. Some people may develop behavioural and psychological symptoms such as wandering, depression or hallucinations as their conditions develop. One in three aged 65+ will develop dementia as they age with the risk of acquiring the condition increasing as they get older.

2.2 Sadly, dementia is progressive condition, which means symptoms gradually get worse and we know getting a diagnosis can be devastating for individuals and families. However, people can live well with dementia for a number of years if they get access to the treatment and support they need early enough, such as the right medication, helping people remember their life stories and continuing to be physically active. There's evidence leading a healthy lifestyle – being active, eating well and managing your weight – can reduce your risk of acquiring dementia. Conversely, some medical conditions – such as high blood pressure and obesity – increase this risk, particularly for vascular dementia.

2.3 There are c. 2,200 residents thought to be living with dementia in Haringey in 2022, and this figure is projected to increase. Figures 1 & 2 contains some facts and figures about the condition and is taken from Haringey's Ageing Well Strategy 2019-2022, which has a section dedicated to Living Well with Dementia. Around two-thirds of people with dementia are diagnosed as such (and with which type of dementia). This figure needs to increase as we know too many people with cognitive impairment are diagnosed at an advanced stage of the condition.

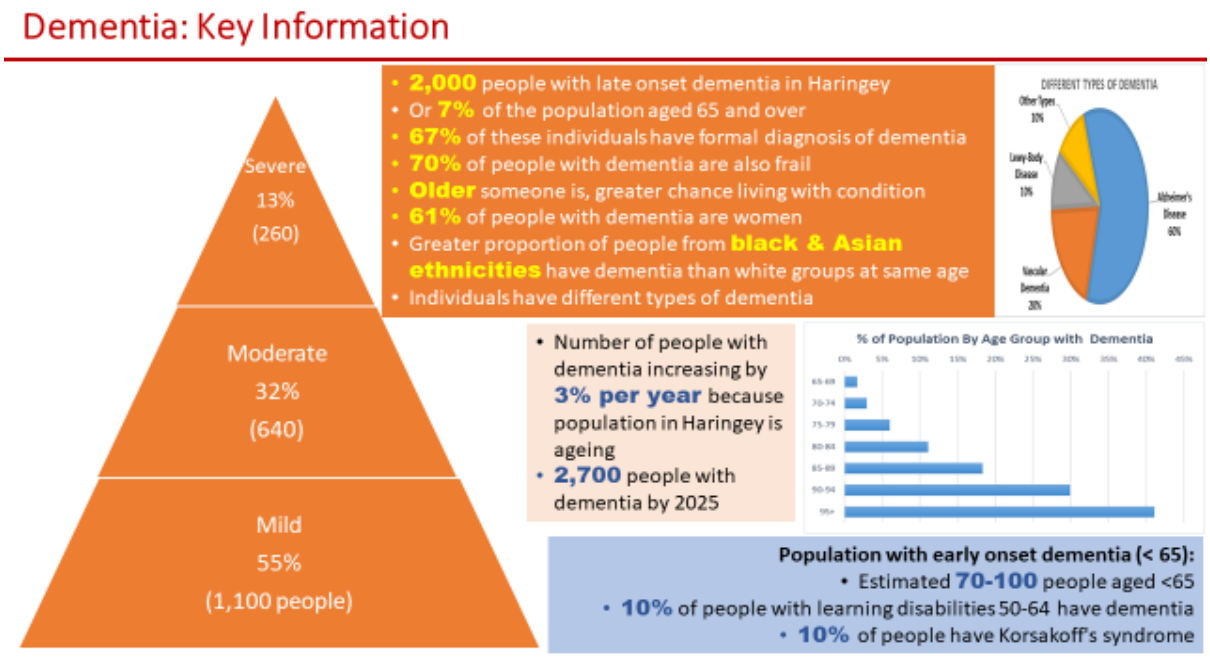


Figure 1 – Facts and Figures on dementia in Haringey (Ageing Well Strategy)

2.4 There are several reasons why not everyone with the condition is diagnosed early, but one is the relatively poor understanding about cognitive impairment and dementia amongst the population, including in specific under-served (often deprived) communities and ethnic groups. This lack of understanding –

including about who to approach to get help - mitigates against people coming forward for diagnosis and help earlier.

2.5 Based on the national approach of the Alzheimer's Society, we are looking to develop a 'Dementia-Friendly Haringey' in which all of us know more about the condition ('Dementia Friends') and organisations, including health and care organisations, but all sorts of other organisations, such as those in the housing, retail, service or financial sectors, can make suitable adjustments to their services to better support individuals. We therefore want to mobilise our communities to play their part in tackling these issues as we know simple changes can make a big difference.

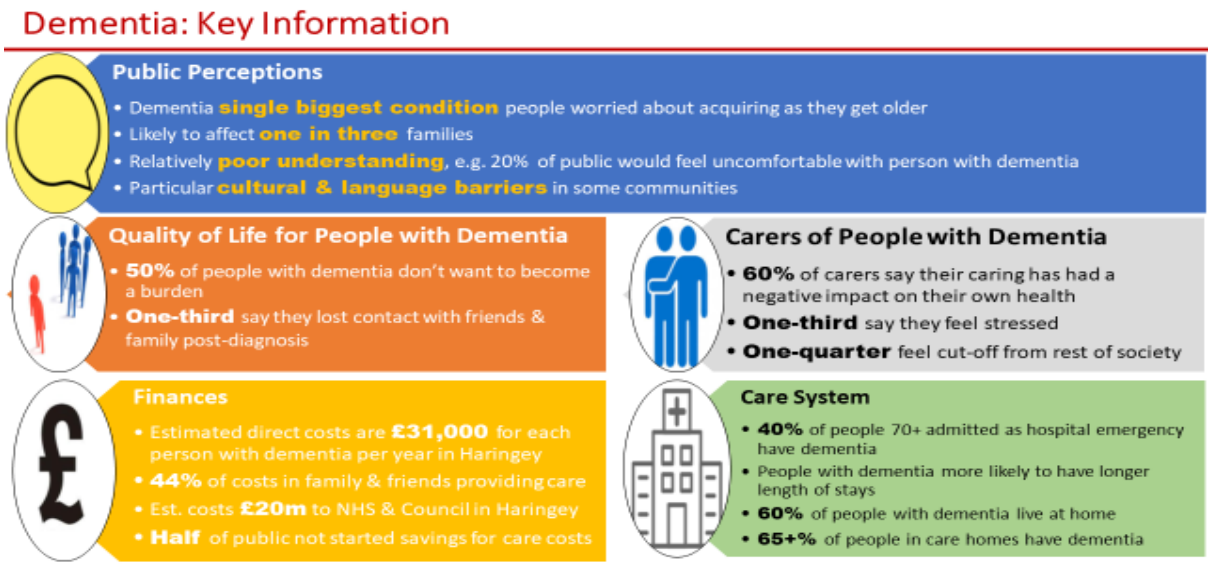


Figure 2 – Intelligence about Dementia (Ageing Well Strategy)

2.6 We know many people living with dementia often have other conditions. The impact on individuals and families may be compounded by personal circumstances, such as living alone. We want to encourage people with dementia and their families to plan for the future and avoid preventable crises, such as being admitted to hospital or care home or carers feeling unable to cope any more. Working together to support people to live well with dementia is vitally important and has its own section in this Strategy.

2.7 Diagnosing the precise type of dementia and organising treatment needs specialist input. We follow NHSE clinical (NICE) guidance in Haringey in which patients with cognitive impairment are referred (e.g. following a hospital episode) or self-refer to their GP practice. The GP will rule out all other medical reasons for the impairment first; if there aren't any obvious reasons or other conditions causing the symptoms (e.g. delirium, adverse reaction to existing medication), the GP will refer the patient onto the Barnet, Enfield & Haringey MH Trust Memory Service for a formal diagnosis. The Memory Service will diagnosis, assess and care plan treatment and support with the patient and families with their GP and others as needed (e.g. a navigator or social worker). The Service and MH Trust provide some services to support individuals and patients, including day opportunities and therapies.

2.8 The primary purpose of the Memory Service is to work with the individual in the first few weeks and months of their diagnosis, and, whilst patients can be reviewed if their conditions change, long-term care of the patient is transferred to primary care, who will continue to monitor individuals' needs. Many people with dementia are also frail or have other physical or mental health conditions. Haringey's Multi-Agency Care & Coordination Team (MACCT), a GP-led multi-disciplinary team of nurses, therapists, pharmacists, social workers, MH workers and VCSE colleagues, manages and care plans the needs of people with significant frailty or multi-morbidity living in the community, some of whom have dementia, with primary care. Similarly, our Enhanced Health in Care Homes (EHCH) team is a nurse-led team managing older people in care homes with a GP lead for each home in Haringey, many of whom have dementia.

2.9 Partners, including people with lived experience, identified a set of actions to better support people with dementia in the Living Well with Dementia section of the Strategy. Whilst some of these actions have progressed (e.g. expanding our EHCH or MACC Team), the pandemic impacted on our ability to progress all our of improvements over the last 2 years.

2.10 Services were also disrupted during the pandemic and some key services, including the Memory Service and face-to-face day opportunities at the Haynes Day Centre and BEH MH Trust's Tom's Clubs were closed during the height of the pandemic. In addition, there is a continued legacy of the pandemic, with face-to-face number of patients at Haynes Day Centre for example lower than they were pre-pandemic, and, as with all care services, there are issues with workforce recruitment, retention and sickness absence services are managing.

2.11 These services have now re-opened and have also adopted new ways of working, e.g. digitally enabled virtual contact with clients to keep in touch. GP and hospital consultant referrals to the Memory Service are now only slightly lower than they were pre-pandemic – around 400 per annum – and our diagnostic rate in Haringey has recovered, so that about two-thirds of patients likely to have dementia are diagnosed on GP registers currently (similar to pre-pandemic levels). This recovery was achieved due to the dedication of Haringey's primary, community and mental health staff, e.g. the overall number of patient consultations is now c. 25% higher than it was pre-pandemic, with the largest increase in practices serving more deprived neighbourhoods.

2.12 Working with people with lived experience with dementia and multi-agency professionals, Haringey developed an aspirational pathway of support for people with dementia and their families. Appendix 1 summarises this journey. Its key features are to provide as seamless and holistic support as possible to better support older adults from acquiring the condition (e.g. ensuring more older people are physically active and adopt healthy lifestyles), through to encouraging people to come forward earlier for diagnosis and treatment, and support as their condition(s) advance.

2.13 However, listening to the experience of people with dementia and carers, partners acknowledge we could do more to better support people with dementia as we recover from the pandemic. We are working closely with the Dementia Reference Group, a group of people with lived experience of dementia, to help

us understand and guide priorities for improvement. Key areas highlighted to us by patients and carers include the need to:

a. Work with under-served communities and groups in Haringey to raise awareness about cognitive impairment and dementia to encourage people and families to spot symptoms and signs and come forward to their GP for help sooner rather than later.

b. Work with health and care professionals and voluntary sector to improve their own confidence and knowledge of working with people with cognitive impairment and dementia and 'what to do next'. We are currently developing an 'Ageing Well' tiered awareness-raising and training programme with Enfield for health and care professionals

c. Relaunch our 'Dementia Action Alliance' through a conference with organisations (those who are members and those who are not) to refresh commitments to better support people with dementia through up to 3 simple actions they can take. Plans are advanced to organise this conference for early in 2023.

d. Appoint a Dementia Coordinator to promote the above activities and encourage further partnerships to emerge to better support individuals.

e. Work with our GP practices, NHS Trusts and Council to improve the consistency, join up and recovery of services for people with dementia post-pandemic and working to 'get the basics right' in services – for example, working with practices with lower diagnostic rates than average. We have recently put a bid in for funding of a dedicated Dementia Facilitator to work with partners to improve their services.

f. Improve the support available in hospital settings, discharge out-of-hospital, for people with dementia and families working with Whittington Hospital and North Middlesex University Hospital and their community as part of 'getting the basics right'. This includes, for example, ensuring that discharge home and onward support is as well-connected and seamless as possible.

g. Work with people with dementia and families to establish a 'dementia support' network post-Memory Service to ensure everyone with a diagnosis has someone – a professional or trained volunteer depending on the level of need - they can turn for help and support and who gets in touch with them routinely if they want and help navigate what can be a complex care system. We want to pilot this approach in 2022/23 with a view to rapidly expanding this solution next financial year. People with lived experience tell us this is the most important priority for them.

h. Improving key solutions to better support individuals, and 'join up' the offer across Haringey and nationally. Many carers told us one thing they would value are things that would improve their ability to cope and better understand the condition, particularly access to psychological therapies. The MH Trust offer access to therapeutic courses to people with diagnosed needs, but we could do more to expand this 'offer' and provide it in different ways and at different points to carers as their loved ones' condition changes.

Similarly, we want to develop a 'hub-and-satellite' model of support, with the Haynes and MH Trust staff acting as 'dementia experts' in our system to provide coordination and expertise to a distributed network of support across the Borough and into localities and communities. Our aim is to provide the help and support people need at the right time as soon after a diagnosis as possible and then onward beyond this point.

i. Improving diagnosis and onward support for younger adults with dementia and their families, including those with learning disabilities (particularly Downs Syndrome), who are at particular risk of early onset dementia.

2.14 We have listened to what people have told us needs to improve and acknowledge there are areas for improvement to better support individuals and their families post-pandemic. We have a wider set of plans overseen through the Age Well Board to take forward these priorities and are currently developing an Ageing Well outcomes framework (incorporating dementia), which will tell us whether we are being successful in progressing this agenda. This framework will incorporate quantitative measures, e.g. whether diagnostic rates are improving and the variation across practices. It will include the views of people with lived experience of dementia – their perspectives on a set of expectations agreed through the Dementia Reference Group – on a range of issues important to them.

2.15 We will feedback routinely our progress against the plan and these outcomes and seek further priorities for improvement through the Reference Group and extended network of residents' and patients' views.

2.16 One area we want to particularly highlight where good progress has been made is the early help information and support for people as they get older. This discussion relates to wider issues associated with ageing well, though an important aspect of the information and support relates to dementia.

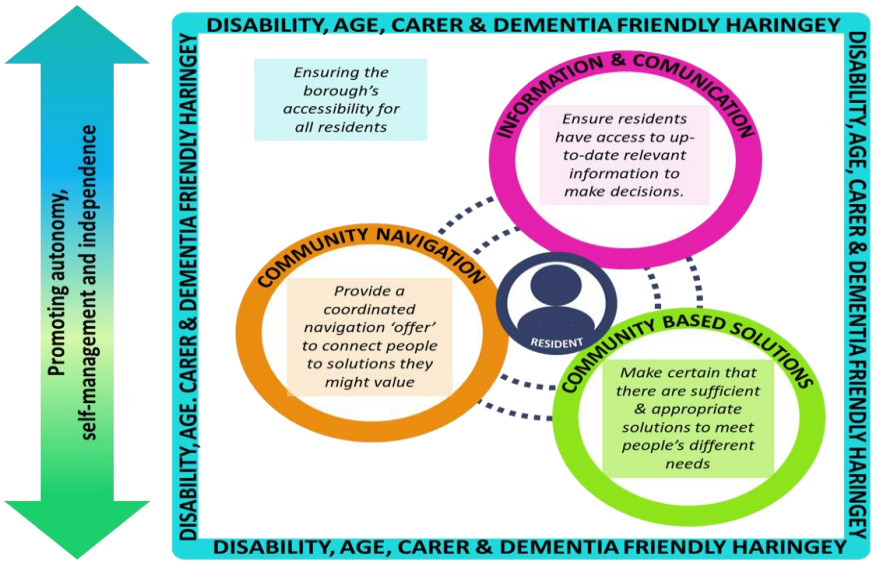


Figure 3 – Our Early Help & Prevention Work-Streams for Ageing Well

2.17 We have progressed this early help project as part of our overall Strategy. Its aim is to improve information, advice and community solutions and assets older people and those with long-term conditions may value. It has three work-streams we are currently progressing, as outlined in Figure 4 below, and we have made progress on all the work-streams:

- Created Age Well Guide and Ageing Well Resources on Council website (with a page dedicated to dementia) and linked to key partners' website, e.g. our NHS Trusts, GP practice sites and voluntary sector organisations. The Guide aimed at those aged 50 and over has hints and tips to look after yourself, and where to go for help, on a range of topics, including one section on memory and confusion. We have distributed 3,000 paper copies across Haringey. Our next steps are to target some of the information to specific groups of individuals and communities that may utilise these messages and to encourage behaviour change built around Public Health's Making Every Contact Count.

- Development of a community of practice (called NavNet) amongst volunteers and statutory sector professionals who have an element of social prescribing or community navigation in their roles or functions – people who can provide front-line advice or connect people to opportunities or services they may value. Participants, which includes staff working with people with dementia, form a 'network of expertise' to mutually support each other in this connection and are connected via a WhatsApp group which pools expertise/contacts to problem solve individual (entirely anonymised) cases together or encourages people to post 'notice board' messages about events, opportunities and services to the group. Membership has increased from 20 to 170 members and we have recently invested in the VCSE to build on NavNet's success. For example, our GP-based social prescribers have around twice as many cases in primary care than the NCL average – and we have expanded the number of such prescribers in Haringey.
- Brought together and developed a range of social opportunities and community assets on a set of themes, for example on:
    - Physical activation, mental well-being and so on. We have recently invested in expanding, for example, our walks programme in parks in Haringey, with a dedicated walk for people with dementia
    - Work with Bruce Castle Museum to promote collection of oral histories of people with dementia. Not only are these life stories a valuable archival resource to the museum, but the act of remembrance stimulates individuals' memory and promotes better management of the condition and sense of purpose. The Museum has since agreed to host monthly get together for people with dementia and carers and has showcased these stories.

Our plans to support people with dementia explore how we might expand and further invest and bring together these opportunities in 2023/24. One opportunity remains to problem solve and develop further community-led opportunities as part of our emphasis on a strength-based approach to supporting individuals with our partners. These opportunities relate to more targeted solutions for people with the condition and carers, e.g. improved

access to therapies, but also ‘normalising dementia’ in mainstream services and solutions.

3. Recommendations

3.1 That the Panel considers how we can sustain and build on improvements to our support for people with dementia and their families.

4. Reasons for decision

4.1 N/A

5 Contribution to strategic outcomes

The Borough Plan 2019-2023, NHS Long Term Plan, Haringey’s Community Strategy and the Better Care Fund.

6 Statutory Officers comments (Chief Finance Officer (including procurement), Assistant Director of Corporate Governance, Equalities)

6.1 Finance and Procurement

This is an update report for noting and as such there are no direct financial implications associated with this report.

6.2 Legal

This is an update report for noting and as such there are no recommendations for action that have a direct legal implication.

6.3 Equality

An EQIA was produced for the overall Ageing Well Strategy and its programme at the time of its publication. The implementation of the AW Programme, and the Living Well Section within it, was seen as positive against several characteristics along age, including better supporting under-served groups and communities, including those living with disabilities, those living in deprived areas and key ethnic groups, e.g. better awareness-raising and support for people from black African and Caribbean groups and some Asian groups who are less likely to come forward with cognitive impairment for professional help. Some of the actions we plan are described above.

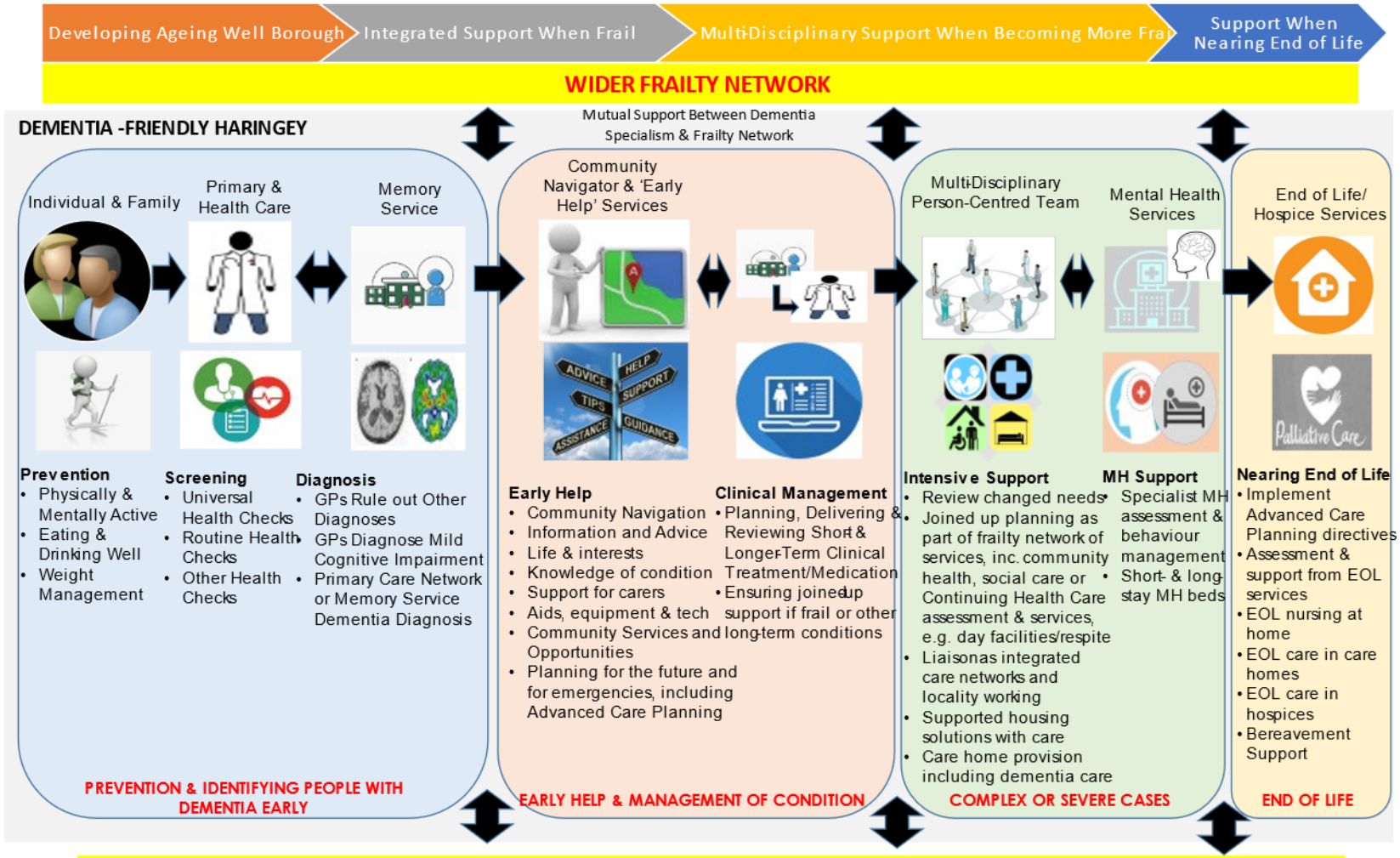
7 Use of Appendices

Appendix 1 – Aspiration Dementia Pathway for Haringey (summary)

8 Local Government (Access to Information) Act 1985

N/A

SUMMARY OF DEMENTIA PATHWAY



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