SCHEDULE 2 – THE SERVICES

A. Service Specifications (B1)

Service Specification No.	
Service	Dementia Community Pathway
Commissioner Lead	Faye Woodward & Emma Bragger
Provider Lead	Alzheimer's Society
Period	1st October 2019 – 30th September 2020 + Optional 1 year
Date of Review	30th September 2020

1. Population Needs

National / local context and evidence base

The term 'dementia' describes a set of symptoms which include loss of memory, mood changes, and problems with communication and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer's disease and damage caused by a series of small strokes.

As people live longer, dementia is an increasing problem across the country and this picture is mirrored in Halton. Although dementia can affect adults at any age, it is most common in older people becoming more prevalent with increasing age. However, this does not mean it is a natural part of the ageing process or inevitable for all older people. Other adults may have an increased risk of developing a dementia, including those with learning disabilities, particularly Down's Syndrome, and people who have excessive alcohol consumption over a long period of time.

According to estimates from Alzheimer's Society, there are 850,000 people with dementia in the UK, with numbers set to rise to over 1 million by 2025. This will soar to 2 million by 2051. One in 6 people over the age of 80 have dementia and there are over 40,000 people under 65 with dementia in the UK.

Current local estimates show that in Halton about 76% of the people estimated to have dementia have been diagnosed. The estimated prevalence for people over 65 with dementia in Halton is 1270, with 972 of those having had a diagnosis (as at April 2019). Of the 972 currently diagnosed, 764 have received their 12 month review care plan carried out by their GP.

Nationally, and locally, it is clear that dementia is one of the biggest challenges facing the health and social care economy. It is a complex condition with widespread effects on the individual, the family and the health and social care system as a whole. Dementia can't be cured, but if it is detected early there are ways it can be slowed down and mental function can be maintained for longer. There are a number of national and local drivers for early detection, and therefore the demand for post diagnosis care and support to meet the anticipated increase in people being diagnosed must be fit for purpose, safe and offer appropriate and timely support.

Having one to one support to provide services navigation, appropriately times information and personalised advice and support forms part of NICE, SCIE and Cheshire and Merseyside Strategic Clinical Network for Dementia guidance and good practice.

2. Drivers for a 1:1 Community Dementia Care Advice and Support service

Building on the previous Halton Dementia Community Pathway service specification (2016- 2019), a review of the services that made up the pathway was undertaken. As a result of the review, and in light of demand for specific parts of the service, the Halton Operational Commissioning Committee approved investment in community provision for a further 12 months + optional 1 year, focusing on the Dementia Care Advisor Service elements.

Service navigation, appropriately timed information, practical advice and support is retained in this service specification, for the person living with dementia, or undergoing investigation for suspected dementia. This is reflective of recommendations made by the NHS North West Coast Strategic Clinical Network for Dementia, of which Halton CCG and Halton Borough Council are members.

The specification also incorporates valuable support for family/informal carers of people living with dementia. NICE guideline [NG97] Published June 2018 'Dementia: assessment, management and support for people living with dementia and their carers' makes the following recommendations in relation to carers of people living with dementia:

- Dementia **carers should have access to advice** on how to look after their own **physical and mental health**, and their emotional and spiritual wellbeing
- Dementia **carers should have access to advice** on planning enjoyable and **meaningful activities** to do with the person they care for
- Dementia **carers should have access to information about relevant services** (including support services and psychological therapies for carers) and how to access them
- **Dementia carers should have access to advice on planning for the future.**
- Carer interventions are likely to be most effective when provided as **group sessions**
- Offer a range of activities to people living with dementia to promote wellbeing that are tailored to the person's preference

Other policy drivers to provide 1:1 dementia specific advice and support in the community comes from the national 'Living Well with Dementia: A National Dementia Strategy', which aimed to ensure that significant improvements are made to dementia services across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care, which .

The Prime Minister's Challenge on Dementia 2020 has also provided a framework for action to deliver major improvements in dementia care and research. The ambition is that by 2020 England will be recognised as:

- the best country in the world for dementia care and support and for people with dementia, their carers and families to live; and
- the best place in the world to undertake research into dementia and other neurodegenerative diseases

The Care Act 2014 is designed to create a new principle where the overall wellbeing of the individual is at the forefront of their care and support. To promote individual wellbeing,

their needs, views, feelings and wishes should be considered in all aspects of their wellbeing from physical and mental health, through dignity and respect to control over their daily needs, access to employment, education, social and domestic needs and the suitability of their accommodation. Whilst the Act incorporates care and support across the board, when thinking about how dementia services are developed, the Local Authority and health care partners need to considerthe following:

• access to services that help prevent their care needs from becoming more serious
• access to good information to help them make informed choices about their care and support have a range of good care providers to choose from
• the public know how to access independent financial advice
• the public know how to raise concerns over the safety or welling being of someone with care needs

'Living well with dementia in Halton **'** local strategy committed to providing services that meet the following Dementia Pledges, which complement the person centred outcomes devised by the National Dementia Partnership:

- You will be diagnosed early
- You will be supported to understand information so that you can make good decisions and
- you know what you can do to help yourself and who else can help you
- You will get the treatment and support which are best for your dementia and your life
- Those around you and looking after you are well supported
- You will be treated with dignity and respect
- You will be supported so that you can enjoy life
- You will be supported to feel part of a community and be inspired to give something back
- You will be supported to ensure that your end of life wishes will be respected. .

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3. Service Description

- **Use an assessment process** to work with the person to clearly identify their, and their carer's, information, advice and practical support needs.
- **Develop a personalised support plan**.
- **Accurately record and maintain records** of people who use the service in line with GDPR requirements.
- **Deliver pre diagnosis information and support** – written and verbal (telephone and/or face to face)
- **Deliver post diagnosis information for person living with dementia and their carer** delivered in a timely and appropriate manner – i.e. written and verbal, telephone and/or face to face, condition specific, carers support opportunities, advanced care planning and end of life matters.
- **Provide a named contact** for the person living with dementia and their carer
- **Develop an understanding of local support/activities and statutory support**

- **Provide navigation and signposting** and facilitate access to appropriate support services – dementia specific services, support and activities, or universal, non-dementia specific services.
- **Offer regular review** of the person's support plan with the person and/or their carer, adding to/updating the support plan as appropriate.
- **Offer regular 'keep in touch' service** of people not actively engaged in the service to offer support at regular intervals.
- **Support people with advanced care planning** through provision of information written/verbal and specialist and community support (i.e. Admiral Nurse) for person living with dementia and their carers.

4. Aims of the Prime Provider

- To provide good quality Dementia Advisor/Support service from pre-diagnosis right the way through to end of life, as defined by *Dementia: assessment, management and support for people living with dementia and their carers NICE guideline [NG97]*, specifically section 1.11.2-1.11.5 and *Social Care Institute for Excellence Dementia - Support following diagnosis,* which highlights key messages from the research on post-diagnostic support for people with dementia and their carers.
- To provide a seamless information, advice, support and keep in touch service for people:
  - Under assessment for a suspected dementia diagnosis
  - For people with a diagnosis of dementia
  - For informal carers (family, friends) of people under assessment or diagnosed with a dementia
- To support wider work on the prevention and early intervention agenda
- To support a reduction in hospital admissions for people living with dementia

5. Service Model

- There will be one provider of the Dementia Care Advisor/ Support Service and Keep In Touch Service
- People will be referred to the service by the Later Life and Memory Service (LLAMS) upon diagnosis, unless they have 'opted out' of the referral. People can choose to be referred at a later date, even if they have opted out upon diagnosis.
- People already dignosed can be referred by the LLAMS team, other voluntary, community or statutory agency, or self refer, at any time in thier dementia journey.
- The service will contact people referred to the service within 48 hours by telephone, or other preferred method (ie written/email) for the service to explain the support on offer and check the person's information, advice or support needs at that time
- The service will 'case load' people who engage with the service between the Dementia Care Advisor and Support Worker, dependent on the complexity of their needs.
- The service will actively engage with the LLAMS team and the Halton Admiral Nurse Service.
- The service will maintain a 'Keep in Touch' register to contact people who do not actively engage with the service at the point of referral and make regular contact with them.

6. Access to Service

6.1 Population covered

The pathway will be available to all adults residing in Halton who require information about dementia, are under assessment for suspected dementia or have had a diagnosis of dementia, and those caring for someone with dementia.

6.2 Any acceptance and exclusion criteria and thresholds

This would be based on individualised risk assessments undertaken by the service and all referring organisations would be expected to share information that may influence a risk assessment.

6.3 Accessibility/acceptability

The service may be provided in the person's own home or other community based location. The service must satisfy their own risk assessment for lone working and health and safety to facilitate community based working.

6.4 Referral criteria & sources

- Self-referral
- Referral from other health/social care professionals

6.5 Referral route

Local number and secure email address

6.6 Response time & detail and prioritisation

- Referrals to be contacted within 48 hours

6.7 Operating hours of service

A minimum of Monday - Friday 9am – 5pm, with the option to become more flexible should the need arise.

6.8 Interdependence with other services / providers

This list is not exhaustive:

- Primary Care
- LLAMS
- Social Care Team
- Carers Centre
- Admiral Nurse Service

- Age UK
- Welfare Services
- Legal Services
- Wellbeing Enterprises

6.9 Relevant networks and screening programmes

- Dementia Action Alliance (DAA)
- Alzheimer's National Society

7. Outcomes

7.1 NHS Outcomes Framework Domains & Indicators

Domain 1	Preventing people from dying prematurely
Domain 2	Enhancing quality of life for people with long-term conditions
Domain 3	Helping people to recover from episodes of ill-health or following injury
Domain 4	Ensuring people have a positive experience of care
Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm

7.2 Locally defined outcomes

Pathway Element	Outcome	Indicator	Measure
Named Dementia Care Advisor / Support Worker to assess, implement support and review the person's/carer's needs	People have access to a named contact so they know who to contact if they require information. People have their needs assessed at regular intervals, and support plans implemented and updated to meet their changing needs	People using the service report that they feel supported and informed	Number of people accessing Dementia Care Advisor/ Support Worker service with a named contact.
Dementia services navigation support from Dementia Care Advisor/Support Worker	People are empowered/supported to navigate services related to their dementia journey including statutory and non-statutory services such as:	People using the service report that they are supported to navigate and understand their dementia journey through access to other services	Number of people signposted and/or referred to other support services. Service user satisfaction

	• health and social care services • community / voluntary sector support • services and organisations related to information, activities, general health, wellbeing • Services that support the role of the informal carer.		survey/feedback form
Information provision from Dementia Care Advisor/Support Worker	People with dementia and/or their carer are informed about understanding the diagnosis, choices around health and wellbeing, local support groups and activities, legal matters and welfare rights. Information is provided at a time that is appropriate to the person and in a format that is most appropriate for them ie telephone, face to face, written	People using the service report that they feel informed about the things that they want to know about, at an appropriate time and in an appropriate format.	Service user satisfaction survey/feedback form
Keep in Touch calls from the Dementia Care Advisor / Support Worker	People who are not actively engaged with the Dementia Support Worker / Advisor at the point of initial referral understand that they can access the support at a time that suits them and that the service will undertake regular 'keep in touch' calls at intervals to be determined	People report that their needs are understood. People report that they know how to access support, at a time during their dementia journey that suits them	Number of people not actively engaged in the pathway at point of referral, that have had a follow up contact Service user satisfaction survey/feedback form

8. Applicable Service Standards

8.1 Applicable NICE Dementia standards

- *Quality Standard 4* - People with dementia are enabled, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice.
- *Quality Standard 5* - People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships
- *Quality Standard 8* People with dementia have opportunities, with the involvement of their carers, to participate in and influence the design, planning, evaluation and delivery of services.
- *Quality Standard 10* People with dementia are enabled, with the involvement of their carers, to maintain and develop their involvement in and contribution to their community.

8.2 Applicable standards set out in Guidance and / or issued by a competent body (e.g. Royal Colleges)

- Department of Health (2015) Prime Minister’s challenge on dementia 2020
- NHS England (2015) Enhanced Service Specification : Facilitating timely diagnosis and support for people with dementia 2015/16