



L I F E S T O R Y N E T W O R K

Dementia Action Liverpool

Report on the Desktop Review of Policy and Practice to Support the Refresh of the Liverpool Dementia Strategy

7th September 2018

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Introduction

This report is written in response to one of two packages of work that Life Story Network (LSN) was commissioned to undertake in support of the Dementia Action Liverpool in refreshing the local dementia strategy.

When undertaking this desktop review, it is important to recognise that there has been a plethora of national guidance published over recent years relating to the care and support of people with dementia and their carers – leading to a recent comment that “*you need guidance for the guidance*”¹. When reviewing the plethora of policies, we have focused on the most pertinent ones and distilled the key messages which need to be considered in the refresh of the dementia strategy (see Appendix A). The most important ones which have been included are:

- [Dementia Finding housing solutions](#) (2014)
- Alzheimer’s Society – [Dementia UK Report](#) (2014)
- [Prime Minister’s challenge on dementia 2020](#) (2015)
- The Mental Health Foundation [Dementia, rights, and the social model of disability - A new direction for policy and practice?](#) (2015)
- [Challenge on dementia 2020: implementation plan](#) (2016)
- [The Care Act](#) (2014) and associated [updates /amendments](#) (2018)
- National Dementia Action Alliance Declaration – [Dementia Statements](#) (2017)
- [Beyond The Front Door](#): What ‘home’ means to people with dementia and their carers: Implications for policy and practice (2017)
- [My future wishes: Advance Care Planning \(ACP\) for people with dementia in all care settings](#) (2018)
- [Carers Action Plan](#) 2018 – 2020
- [After a diagnosis of dementia: what to expect from health and care services](#): A guide to the support people should get from local services in England if they or someone they know have been diagnosed with dementia (2018).
- [APPG Inquiry - dementia and disability](#) (2018)
- [The Dementia Care Pathway – Full Implementation guidance](#) (2018)
- [Dementia Friendly Hospital Charter](#) (2018)

¹ Jeremy Hughes, Chief Executive of the Alzheimer’s Society speaking at a National Dementia Action Alliance meeting July 2018.

Executive Summary

We can summarise the core generic principles from national policy and good practice that should be included in the refresh of Liverpool's dementia strategy. These include:

- Active participation from people living with dementia and their family carers –through the work of SURF and tide, DAL have a long and successful track record and through this process people living with dementia and their carers will be co-producing the refresh of the dementia strategy;
- Ensuring that there is a clear focus on a preventative strategy and in particular addressing the known wider determinants of poor health which contribute to dementia. There should be a particular focus around Black and Minority Ethnic (BAME) communities and on the prevention of carer breakdown / crisis;
- Ensuring that individuals and family carers have access to timely and accurate diagnosis - and the appropriate care and support from across the local health and care system post diagnosis, including from universal services, intermediate care services, hospital care services and specialist services;
- Increased and overt focus on equality and a rights based approach - which will assist in minimising the discrimination of people, including those living with dementia and their family carers;
- A focus on increasing independence - real choice and active citizenship for individuals with dementia and what this means for carers;
- Enabling family carers to be recognised in their own right – it has long been recognised that in order for people who have a diagnosis of dementia to live fulfilling lives, this often requires the intense support of their families and friends and those who are unpaid care partners. Often, what is not considered is the human cost to the carers and family members themselves. Carers need to be identified and supported to be active and equal partners;
- Making social inclusion a reality and combating the risks of social isolation – by taking a holistic, person-centred and whole systems approach to supporting the refresh of the strategy, drawing on what needs to be addressed at a community and city level to ensure that social isolation and loneliness, often experienced by people living with dementia and their family carers, are fully explored and addressed.

Many of these key messages are broadly reflected in the standards set out in the new Dementia Care Pathway. Consequently, at the Dementia Action Liverpool Steering Group meeting (August 22nd), it was agreed that the structure of this review needs to be focused and driven by what local people with dementia and carers told us (***what really matters***) and how this compares against the national standards as set out in [The Dementia Care Pathway – Full Implementation guidance](#) (2018).

In this report, we have used the steps in the Dementia Care Pathway (Diagnosing well, Supporting well, Living well and Dying well) as chapters and summarised what people with dementia and carers have told us about local services and support; and compared this with what is now expected under the new standards in the Dementia Care Pathway. Where possible, we have also included examples of what is working well and what needs to be improved. Within each chapter, we have cited examples of good practice from across the UK. In recent meetings, three clear priority areas have emerged for specific attention. These include End of Life Care and Post Bereavement Support, Short Breaks and Out of Hours Support. We have enlisted the support of the Strategic Clinical Networks and requested examples of good practice in these specific areas. Results from this request are expected by the end of September.

In addition, we have also taken account of the excellent work undertaken locally including the '*Housing and Support for Older People in Liverpool - a Sub-Report of the Future of Supported Housing Research*'², '*Review of respite services for people living with dementia and their carers*'³, and the '*Care Home Improvement Strategy*'⁴. The findings from these reports are used to assess what additional gaps remain to be addressed when compared with the progress report on the existing dementia strategy published in 2016. A mapping of progress and the emerging priorities that need to be considered in the refresh of the dementia strategy are outlined in Appendix B.

This report is intended to contribute to the development of an '**AS IS**' position paper, from which the Steering Group can agree on key lines of enquiry to be taken forward in the next phase of the work including using the material to inform the future community engagement events planned for October.

² Imogen Blood & Associates in partnership with Housing & Support Partnership, HGO Consultancy and Liverpool City Council (2017)

³ James L (2016) Review of respite services for people living with dementia and their carers

⁴ Liverpool City Council (undated) Care Home Improvement Strategy

Chapter 1 Diagnosing Well

It is generally understood that getting a timely diagnosis, along with the facts about dementia – in terms of the nature of the disease, how it can be recognised and managed and the level of support at every stage of the dementia journey – not only enables people to prepare for and deal with the disease, but also allows the whole family’s needs to be taken into consideration. The following standards are set out as part of the Dementia Care Pathway:

- ‘I was diagnosed in a timely way’
- ‘I am able to make decisions and know what to do to help myself and who else can help’.

The following provides a summary of:

- what mattered to local people with dementia and their carers
- how this compared to the new national standards
- what works well and
- areas for improvements

| The Dementia Care Pathway Standards - Diagnosing well | What matters to local people with dementia & carers |
|--|---|
| <p>Initial assessment in non-specialist</p> <p>Settings</p> <ul style="list-style-type: none"> • cognitive neurology clinics or neurology services • geriatric or old-age medicine clinics/services, • through acute (medical) trusts | <p>What works well</p> <p>Discussions at the two engagement events about receiving a diagnosis and post-diagnostic support highlighted a number of areas of good practice, as well as areas where changes still need to be made. One of the examples of excellent practice given was the Memory Service run at Mossley Hill Hospital. The service offers practical advice and emotional support to people diagnosed with dementia and carers. Its post-diagnostic support groups and cognitive stimulation sessions were highly rated by those taking part in the engagement events. The Memory Service has been accredited as excellent over 3 cycles of the Memory Services National Accreditation Programme for providing a high quality of the service and the</p> |

| The Dementia Care Pathway Standards - Diagnosing well | What matters to local people with dementia & carers |
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| <ul style="list-style-type: none"> • GP-led clinics/services supported by specialist advice and assessment from one or more of the services above • integrated services, with co-location and/ or joint working between one or more of the providers above • via secondary mental health care providers, either as stand-alone memory clinics or services, or integrated with older adult community mental health services | <p>involvement of people with dementia and carers.</p> <p>Other examples of good practice included post-diagnostic support offered by a number of GP surgeries across the city. Carers in particular highly rated the practices where GPs are aware of their needs:</p> <p><i>‘Some GPs are excellent ‘As a carer I get a priority appointment. They are aware that if I get sick, who’s going to care for the person with dementia?’</i></p> <p>Areas for improvement</p> <ul style="list-style-type: none"> • Make post-diagnostic support similar to that offered by Mossley Hill Hospital equitable across the city – available to people with dementia across all localities • Improve the availability of the cognitive stimulation sessions – from time-limited involvement over the short-term to ongoing sessions • Some described the promptness of the diagnosis as ‘sporadic’, and talked about difficulties with having access to timely appointments. • GPs’ knowledge of post-diagnostic support services available in the city and their responsiveness to an individual’s request for an assessment were perceived to be of varying quality • Improve GPs’ understanding of health and wellbeing needs of carers through a better |

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| The Dementia Care Pathway Standards - Diagnosing well | What matters to local people with dementia & carers |
| | <p>record keeping, e.g. the carers' register</p> <ul style="list-style-type: none"> • A proposal for including the establishment of clinics for carers in GP practices, based on the Well Man/Well Woman model in the updated Dementia Strategy was put forward: <p><i>'Well Carer' clinics – like Well Woman clinics. Could include a physical health check as well as mental health.'</i></p> • There were calls for improvement to the continuity of care through improving access to the same GP • Needs of younger people living with dementia need to be better understood and services should reflect these specific needs • Make GP practices dementia-friendly through prioritising the needs of people with dementia and carers, and having information packs available. • Practice pharmacists service was highlighted as a positive development because of its flexibility. Having the same pharmacist who is a familiar face was valued as a positive experience |
| Named coordinator of care and care Plan Facilitate choice, independence and person-centred care, including | What works well People with dementia and carers taking part in engagement events highlighted the positive role of Care Navigators in offering tailored post-diagnostic support. However, insufficient numbers of Care Navigators available across Liverpool were highlighted as one of the areas for improvement: <i>'The system should be that if you're diagnosed with dementia you should be put in touch with</i> |

| The Dementia Care Pathway Standards - Diagnosing well | What matters to local people with dementia & carers |
|--|---|
| <p>seeking</p> <p>Informed decision-making and valid consent where appropriate through use of advance statements and decisions and the Mental Capacity Act 2005.</p> <ul style="list-style-type: none"> • Signpost people with dementia and their families and carers to local support services, to ensure continuity of care. • Jointly develop and review the care plan with the person and their family and/or carer at least every 12 months, to ensure that it is still applicable and effective. • Ensure the person's physical and mental health is monitored and that they can access appropriate treatment | <p><i>a Care Navigator, but there are not enough of them'</i></p> <p>It was also suggested that people with dementia and carers in Liverpool would benefit from the establishment of a 'one stop shop' for all-encompassing advice around dementia services across the city. It was emphasised that this should be a staffed service rather than a virtual hub.</p> <p><i>'This should be the glue that binds all things is, you can go in and have a conversation. It's very important that it's a physical place rather than one person such as a Care Navigator or an online service'.</i></p> <p>The 'one stop shop' would serve as the universal point of contact for people with dementia and carers linking them to existing services available in the city and providing benefits advice and information about services available to carers.</p> <p>Areas for improvement</p> <ul style="list-style-type: none"> • The importance of advanced care planning at an early stage of dementia involving the person with dementia and the carer was discussed. The plan should entail the outline of risks such as falls, and rights and wishes such as refusing hospitalisation. Support with planning should be included in the post-diagnostic support package and staff should be trained in providing it. • The quality of post-diagnostic support provided by GPs was seen as varying significantly across Liverpool, with some GPs reportedly not providing any signposting or advice on post-diagnostic support. It was suggested that more information should be made available at the point of diagnosis, for example, a pack containing information about available services, numbers of helplines and so on. |

Examples of Good Practice – Diagnosing Well

The review from the available evidence has highlighted the following examples of good practice.

Islington Memory Service

[Islington Memory Service](#) is based within Ageing and Mental Health Services in Camden and Islington NHS Foundation Trust.

Steps to delivering a timely diagnosis and care plan

1. Within 2 weeks of referral, an **initial assessment** is arranged with the team doctor at the person's house. This is typically in the presence of a family member or carer. During the assessment, the person with suspected dementia is asked if they wish to know the results of the diagnosis and who else should be informed. The process of assessment, potential outcomes and corresponding care-planning options are then discussed.
2. A **full assessment** is conducted. If dementia is suspected and the person has not had a **CT scan** in the past 6 months, a scan is arranged to confirm the diagnosis and dementia subtype.
3. If they wish to know, the person is told their **diagnosis** by a team doctor. They are given verbal and written information on the diagnosis, and an overview of the local post-diagnosis pathway and intervention options.
4. The **care plan** is discussed and agreed with the person.
5. Two weeks after diagnosis, an appointment is arranged with a '**dementia navigator**' (named coordinator of care). The dementia navigator works jointly with the person, signposting them to relevant local services and providing information. Every effort is made to promote easily accessible and flexible care. If a person has been prescribed medication then ongoing monitoring, signposting and support will be provided by a nurse. If a person is not prescribed or does not tolerate medication, or chooses not to take up treatment, ongoing signposting and support is provided by the dementia navigator.

Meeting the recommended response time of 6 weeks

The average response time to diagnosis is 11 weeks, with a maximum of 12 weeks. The service is working proactively with commissioners to promote efficiency across the diagnosis pathway and further reduce waiting times. Waiting times for CT scans have been identified as the source of most delays, and a clinical support worker has been appointed to support and improve this process. This includes booking the scans, prompting people to attend (and accompanying them to their appointment when necessary), requesting the results and booking the post-diagnostic appointment.

Further information

Further information about Islington Memory Service - contact Helen Souris, helen.souris@candi.nhs.uk

South Bucks Memory Service

Until the CCG merger in early 2018, South Bucks Memory Service operated across two sites in High Wycombe and Amersham using a 'one-stop assessment' framework for diagnosis.

Steps to delivering a timely diagnosis and care plan

1. Before the initial assessment, a physical examination and dementia blood screening are carried out at the **GP practice**. Referrals are then made to a **single point of access**, and triaged daily to ensure they are appropriate and complete. A decision is made regarding the best place of assessment – either at the main clinic, the GP surgery or at home.
2. A protocol developed in collaboration with radiologists is used to decide whether to offer the person a **CT scan** or **MRI** before the assessment.
 - a. A **personal registration form** is sent to the person to collect information on:
 - i. demographic factors
 - ii. personal history
 - iii. preferences about sharing the diagnosis with family members and agencies such as social services whether they wish to be contacted about future research opportunities.
3. The **initial assessment** is carried out by a doctor and a nurse, or by an assistant psychologist. The person with suspected dementia and their family/carer are interviewed jointly and separately. During the appointment, results and investigations are viewed on an electronic database. Head scans may be viewed via a picture archiving and communication system, and shown to the person to demonstrate brain changes in a more detailed way. A quarterly review of scans is conducted in a meeting with a consultant neuroradiologist.
4. Where the person exhibits an unusual, complex or early-onset form of dementia, a **referral for detailed neuropsychological assessment** is made.
5. A **diagnosis** is made in a supportive and sensitive manner, and time is set aside to address the person's questions and concerns. General recommendations are made to slow the rate of progression, including: healthy living advice
 - a. cognitive stimulation
 - b. monitoring of vascular risk factors
 - c. avoidance of high-risk factors (such as excessive alcohol consumption)
 - d. advice on the prompt treatment of infections should they occur.
6. The clinician who completed the assessment acts as the person's **key worker** (or named coordinator of care) and develops a **care plan** with them.
7. After 2 weeks, telephone contact is made with the person and/or their family/carer to **assess progress** and ask about any side effects. Further medication is then prescribed as appropriate.
8. A 3-month **review of medication** (where applicable) occurs with the key worker. Afterwards, the person is often **discharged to their GP's care**.

9. **Routine review** is expected to occur once or twice a year as stipulated in the local shared-care protocol.
10. South Bucks Memory Service had an average wait of 4.3 weeks in 2017, well within the recommended response time for diagnosis. In addition to using a 'one-stop assessment' framework, the service introduced a 'choose and book' service (now known as NHS e-referral). In January 2014 this was used in 20% of referrals to the service and offered a greater choice of venue and time of appointment, shorter waiting time to assessment and a more positive patient experience. As part of this, the 'Memory Assessment Closer to Home' clinic also ran from rural GP surgeries. The service promoted efficiency by also ensuring that high-quality referral information was received. Specific training was offered to local primary care services to improve awareness and the quality of referrals.

Further information

Further information contact Dr Brian Murray, Consultant Older Adult Psychiatrist and Associate Medical Director Brian.Murray@oxfordhealth.nhs.uk or Dr Rohan Vanderputt, Consultant Older Adult Psychiatrist, Rohan.Vanderputt@oxfordhealth.nhs.uk

Stockport Memory Assessment Service

[Stockport Memory Assessment Service](#) is based within the Pennine Care NHS Foundation Trust. Stockport has the oldest age profile in Greater Manchester: currently 19.4% of people are aged 65 or older, which is likely to rise to 21.8% by 2024. Stockport has the highest dementia prevalence of Greater Manchester.

Steps to delivering a timely diagnosis and care plan

People are usually seen within 6 weeks of referral. The assessment takes place in the patient's home or a clinic, and is carried out by an appropriately skilled person from a multidisciplinary team. Following this assessment, a **provisional diagnosis** is given.

The service minimises its non-attendance rate by carrying out a high volume of home visits. These visits can also improve the quality of the assessment by enabling clinicians to get a better picture of how the person and carer are coping. A **formal diagnosis** is confirmed and finalised within 12 weeks, supported by CT or MRI scan results. The consultant delivers the diagnosis and organises a **treatment plan** as necessary.

Post-diagnostic interventions

Once diagnosed, the person with dementia and their family or carers receive an **information pack** with relevant services and support. A **dementia link nurse** will visit the person with dementia and will follow-up with them regularly if they are prescribed medication.

Each GP practice has a named dementia specialist link nurse from the memory service to offer bespoke training, review the dementia register together with the lead GP, share information and discuss access to **post-diagnostic support**. In addition, people living with dementia are referred back to their GP when they are stable on medication and have received all relevant information and advice.

Meeting the recommended response time of 6 weeks

The service currently meets the recommended response time, with 98% of people seen and diagnosed within 6 weeks of referral. This has been achieved by:

- carefully triaging all referrals to ensure a timely appointment is offered
- obtaining scans within a 6-week period
- dementia link workers working in partnership with local GPs
- strong links between the memory service, local authority and the third sector, which all contribute to a coordinated post-diagnosis work stream
- seeing people living with dementia in their own homes and other places of residence (care homes).

The service has developed a shared-care pathway, which allows people living with the early stages of dementia to be managed in primary care (with support from the memory service). People are often only referred back to the memory service on average 4 years after diagnosis, when their needs have changed.

The service received additional funding to increase capacity and to support GPs in undertaking dementia monitoring reviews and attend training. As a result of this, many GPs report feeling more confident about managing dementia. The shared pathway is supported through the appointment of four link nurses in the memory service and an Alzheimer's Society post-diagnostic support worker for vascular dementia.

The service has implemented a 'dementia local enhanced service' since 2013. This includes developing a 'dementia action plan' for each practice, training staff to undertake dementia reviews and raising dementia awareness.

Further information

For further information contact Nicole Alkemade, Older People's Joint Commissioning Manager at NHS Stockport Clinical Commissioning Group nicole.alkemade@nhs.net

Lancashire Memory Assessment Service: learning disabilities

[Lancashire Memory Assessment Service](#) specialises in providing assessment and diagnosis for people with suspected dementia. The service uses a specialised consultation model to maximise the capacity and flow by reducing the waiting time between the initial assessment and the diagnosis. There is a standard pathway and an enhanced pathway, which is tailored to meet the needs of people from specific populations, including people with learning disabilities.

Delivering NICE-recommended care for people with learning disabilities

Referrals are made to a **single point of contact** and are screened for risk indicators. They are then passed to the memory assessment service and triaged via telephone, to identify whether the standard or enhanced pathway is more appropriate. All people with suspected dementia and identified learning disabilities are allocated to the **enhanced pathway**.

The **specialist interest nurse** ensures that assessments for people on the enhanced pathway are booked within 3 weeks and have designated time for meeting with the specialist learning disabilities psychologist.

An **initial assessment** is then conducted, which involves taking a comprehensive medical history, symptomatology, performing risk assessment and blood testing. On the enhanced pathway, people are allocated to a specialist nurse and a wider multidisciplinary approach to assessment is used, which includes psychologists, occupational therapists and learning disability services. Referrals may also be made for brain scans.

Diagnosis is made by the psychologist or the doctor. **Easy-read materials**, including pictures, are used to share the diagnosis with the person with learning disabilities, and an **agreed care plan** is developed with them.

Following diagnosis, the person has one session of **post-diagnostic support** focusing on exploring the diagnosis and the support that is available. Training is also provided to families and carers on how to support the wellbeing of the person living with dementia. If the person is prescribed medication, they will remain under the care of the specialist nurse. Alternatively, the person may be discharged back to the learning disabilities team or their GP for regular review.

Further information

Further information contact Linda Dickens, Team Manager linda.dickens@lancashirecare.nhs.uk

Chapter 2 Supporting Well

Research has shown the importance of peer support groups for people living with dementia and family carers, not just as a means of providing practical, timely and emotional support to one another based on shared experiences locally, but also as a key influencing voice working with the local commissioners and providers. The [National Dementia Strategy](#) (Department of Health, 2009) stated that the person with dementia (and their carer) should be placed centre stage in terms of saying what is important in their lives and what a good life with dementia looks like. The more recent [Care Act \(2014\)](#) places obligations on local authorities to ensure that people can exercise individual control and choice, with particular attention to the individual's views, wishes, feelings and beliefs.

The following standards are set out as part of the Dementia Care Pathway:

- 'I am treated with dignity and respect'
- 'I get treatment and support which are best for my dementia and my life'

The following provides a summary of:

- what mattered to local people with dementia and their carers
- how this compared to the new national standards
- what works well and
- areas for improvements

| | |
|--|--|
| The Dementia Care Pathway Standards – Supporting Well | What matters to local people with dementia & carers |
| Named coordinator of care and | What works well |

| | |
|--|--|
| <p>care Plan</p> <ul style="list-style-type: none"> • Facilitate choice, independence and person-centred care, including seeking informed decision-making and valid consent where appropriate through use of advance statements and decisions and the Mental Capacity Act 2005. • Signpost people with dementia and their families and carers to local support services, to ensure continuity of care. • Jointly develop and review the care plan with the person and their family and/or carer at least every 12 months, to ensure that it is still applicable and effective. • Ensure the person's physical and mental health is monitored and that they can access appropriate treatment | <p>In relation to signposting, and in addition to the Care Navigators Service mentioned above, people with dementia and carers offered positive feedback on the BAME Dementia Champions project. There were calls for commissioners to continue to fund the project which stopped operating in 2017 (apart from within the Chinese community) following the CCG's withdrawal of funding.</p> <p>The positive role of the Dementia Clinical Network in improving access to post-diagnostic support was highlighted. Although the engagement events revealed mixed experiences of post-diagnostic support, many felt that steps are being taken to ensure equity of access across Liverpool.</p> <p>Areas for improvement</p> <ul style="list-style-type: none"> • Calls to ensure that the equity of access to post-diagnostic support is improved further, ending the 'postcode lottery' • Continue investing in the 'low level support' services such as BAME Dementia Champions Project; fill the gap in services created by the withdrawal of the Alzheimer's Society's provision • Improve identification of and support for people with dementia who live alone: <p><i>'There is no advocate for a person with dementia if there is no carer, no one to find out what's happening and how to access support. I want to see in the new strategy support for people with dementia who live on their own'.</i></p> |
| <p>Management of non-cognitive symptoms and behaviour that challenges – The aim of the intervention will be to improve outcomes and reduce the need for inpatient admission. In some areas, this support may also be delivered by rapid response</p> | <p>The events evidenced that the current provision of out of hours support is seen as inadequate. Experiences of people with dementia living alone were particularly poor, but this was also the case for people with dementia living in care homes. Examples were given of people with dementia who experienced agitation and difficulties having to go to the A&E, being sedated or phoning the police, as there were no other options available out of hours or at weekends. These outcomes were seen as highly inappropriate for people in crisis situations.</p> <p><i>'Out of hours, after 9 p.m. the system stops. I have to call 999 and go into A&E, and I</i></p> |

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| <p>teams or crisis resolution and home treatment teams</p> | <p><i>don't want to do this. Is there a time when the NHS stops?</i></p> <p>Areas for improvement</p> <ul style="list-style-type: none"> • A 24 hour crisis line was proposed as one of the top priorities for the updated strategy alongside CPN availability. It was emphasised that the telephone line must be staffed and not simply providing advice through pre-recorded messages: <p><i>'We need a crisis line but with somebody on the other end, not a recording, who can come out if necessary.'</i></p> <p>There was a consensus that the availability of the 24 hour crisis cover with CPN support would prevent people experiencing crises from relying on the police or ambulance services:</p> <p><i>'We don't want to have to depend on 999 or 111'</i></p> |
| <p>Acute and general hospital inpatient care - If admission is necessary, it should be planned and as brief as possible, to minimise the adverse consequences hospitalisation can have for people living with dementia</p> <p>Liaison mental health - Liaison mental health services can provide assessment and interventions for people with suspected or diagnosed dementia who are in a general hospital</p> | <p>One of the points raised in the discussions was staff training in dementia, including training for hospital staff. It was felt that the training offered to staff was often basic consisting of 'Dementia Friends' information and awareness sessions, which although were described as good, were nevertheless seen as not sufficient. In addition, reliance on online training without face-to-face sessions was seen as poor practice.</p> <p><i>'There should be a test of competencies, including in hospitals... Staff should receive more than Dementia Friends [information session]. Good quality training should focus more on the cultural awareness of staff members.'</i></p> <p>Areas for improvement:</p> <ul style="list-style-type: none"> • Adopt a blended approach to staff training entailing online modules, face-to-face sessions and practical tasks followed by a test of competencies • Offer other opportunities for staff to improve knowledge and competencies around dementia care to drive the change in culture and attitudes to people with dementia and carers |

Examples of Good Practice – Supporting Well

The review from the available evidence has highlighted the following examples of good practice.

Bexley Dementia Pathway

The [Alzheimer's Society \(Bexley\)](#) offers a range of national and local dementia support services for people living with dementia and their carers. One example of local support is the Bexley Dementia Pathway.

A cost–benefit analysis of dementia adviser services in Bexley and West Lancashire indicated the cost effectiveness of implementing this integrated approach.

Delivering NICE-recommended care: named coordinator of care and care planning

At the point of diagnosis, each person is offered an appointment with a dementia adviser (or named coordinator of care) who can signpost them to a range of individualised support. Support may be given face to face, over the telephone or by email, and varies depending on individual circumstances. The dementia adviser also provides emotional support and helps the person work through, or make sense of any difficulty or distress they may be experiencing.

As the person's dementia progresses, they are offered a one-to-one dementia support service assessment and a care and support plan. The dementia support service is delivered to people living in their own home or in the home of their family or carer. However, the service can be delivered in a memory clinic, hospital, or residential home environment in line with the eligibility criteria and the identified outcomes of the care and support plan.

Appropriate referrals to other health and social care services and/or external organisations can then be made by the dementia support service on behalf of the person living with dementia. Reviews are scheduled in at 6 weeks, 12 weeks and 6 months to ensure that the person and their family or carer have managed to access the required support. Individuals are also encouraged to contact their dementia adviser as required.

Further information

Further information contact Jo Vavasour, National Business Development Manager jo.vavasour@alzheimers.org.uk

Sheffield Memory Service

[Sheffield Memory Service](#) offers a range of post-diagnostic interventions to support the mental and physical health and wellbeing

of people living with dementia and their families and carers. Care is delivered across the system, with strong links to social services.

Steps to delivering and reviewing a care plan

1. Following diagnosis, a **collaborative care plan** is developed and agreed with a nurse (or occupational therapist), the person living with dementia and their family or carer.
2. A range of **interventions** may be offered
3. A follow-up appointment is scheduled within 6 months to **review the care plan** (including current medication). The service also offers a daily nurse helpline for intermediate support, using a case management model.
4. The person living with dementia remains with the service, discharged only when in 24-hour care under the local commissioned agreement of GP support.

Interventions for behaviour that challenges

The service works collaboratively with specialist teams in the Sheffield Health and Social Care NHS Foundation Trust (including the community mental health team) to provide support to people living with dementia and coexisting behaviour that challenges. This includes educational interventions as well as access to a rapid response home treatment team. This team works with people who have a diagnosis (or working diagnosis) of dementia and are experiencing some degree of crisis or difficulty affecting their wellbeing. The service is open 365 days a year, from 8.00 a.m. to 8.00 p.m. The team also provides home treatment outside of these hours to people for whom it is part of their treatment plan.

Meeting Centres- Worcestershire and Herefordshire

[The Meeting Centres Support Programme \(MSCP\)](#) provides an innovative way of supporting people with mild to moderate dementia and their families through an evidence-based, person-centred approach. Meeting Centres generally start from a community organisation or group of people recognising that there is a need for more structured support for people affected by dementia in a local community.

It is unimportant who comes up with the idea to initiate a Meeting Centre, because collaboration with other organisations is essential to getting the initiative off the ground. Meeting Centres **were first developed in the Netherlands 25 years ago** and following evaluation of their effectiveness are available throughout the country and part of the standard offer to people with dementia after diagnosis. Currently there are two Meeting Centres in the UK located in Worcestershire and Herefordshire. The programme is being rolled out throughout the UK with a National Lottery grant from the Big Lottery Fund. Dutch research, and now European research, demonstrates that Meeting Centres have positive outcomes for people with dementia and for family

carers.

Chapter 3 Living Well

Over two thirds of people diagnosed with dementia live in their local communities and a third of these live alone. Consequently, we need to work collaboratively with partners in local communities to address the broader determinants of health and wellbeing and enable people to live well with their dementia. Whilst there is the aspiration to ‘live well’ with dementia, for many people with dementia and their carers is far from the reality that they experience on a day to day basis. There is a national focus and imperative to develop ‘Dementia Friendly Communities’, but there is a need to take a more rights based approach that empowers people to participate as equal citizens. The World Health Organisation’s framework [‘Age Friendly Cities’](#) emphasises enablement rather than disability; it is inclusive of all ages and not just “elder-friendly” *“The future of communities across the world will in large part be determined by the response made to achieving a higher quality of life for their older citizens” (p.9).*

The following standards are set out as part of the Dementia Care Pathway:

- ‘I know that those who are around me and looking after me are supported’
- ‘I feel included as part of society’

The following provides a summary of:

- what mattered to local people with dementia and their carers
- how this compared to the new national standards
- what works well and
- areas for improvements

| | |
|--|--|
| The Dementia Care Pathway Standards – Living Well | What matters to local people with dementia & carers |
| Person-centred support <ul style="list-style-type: none">• appropriate housing | What works well |

| The Dementia Care Pathway Standards – Living Well | What matters to local people with dementia & carers |
|--|--|
| <p>provision such as extra care housing</p> <ul style="list-style-type: none"> • support in maintaining relationships at home and in the wider community • support in maintaining independence, including dementia-friendly communities, advocacy services, homecare services, campaign services and information provision • Support in engaging in meaningful daily activities that are person-centred and may take place on an individual or group basis, in a variety of settings • support, training and advice for carers, including respite care, peer support groups and training courses, or support provided in the work environment • practical support, such as with transport | <p>A few positive examples of what can help people with dementia and carers to live were offered. These include the work of the DAA on helping to improve awareness of dementia and to break down social stigma. Dementia Champions and organisations working to make Liverpool more dementia-friendly are also seen as an effective force for change.</p> <p>SURF was highlighted as an important source of information, peer support and voice for people with dementia and carers:</p> <p><i>‘I meet other people, I have opportunities to put a little back in and support other people’</i></p> <p><i>‘SURF creates connections and friendships’</i></p> <p><i>‘Informal peer support as offered by SURF is crucial’</i></p> <p>The Occupational Therapy (OT) service received positive feedback although it was also highlighted that OT facilities and adaptations such as wet rooms through Disability Facilities Grants were not available to people with small private pensions even though they could not afford to pay for the adaptations independently. Often equipment offered to people with dementia is not suitable for their needs, an example was given of raised toilets seat only available in white.</p> <p>People with dementia and carers pointed out that Direct Payments work very well for some as they offer choice in commissioning care provision:</p> <p><i>‘We could go anywhere, to any agency, we had this freedom’</i></p> <p>However, some felt the facility is not well known and poorly promoted by social services, potentially because it is perceived as an administrative burden.</p> <p>Other good practice examples of health and wellbeing provision cited were cycling activities</p> |

| The Dementia Care Pathway Standards – Living Well | What matters to local people with dementia & carers |
|---|--|
| | <p>offered by Healthiness, Keep Fit classes and services offered by Everton in the Community. These were seen as an important source of physical activity positively affecting physical and mental wellbeing.</p> <p>Areas for improvement</p> <ul style="list-style-type: none"> • In relation to housing the issue with the lack of information around housing options was raised. Often people with dementia and carers who want to stay in their own home are not aware about options available to them, such as applying for a grant to carry out house modifications. • There were calls for a better use of assistive technology and for making information about adaptations and technology clearer and available in a variety of formats rather than online only. The positive role of technology is enabling people to stay connected with families living elsewhere was given as an example of good practice. • In relation to homecare services, their inflexibility and the lack of understanding of dementia among staff were highlighted. There were calls for a better training for staff and for improving home care providers’ capacity to respond to changing needs. • Carers called for an improvement to the Carers’ Vouchers scheme citing its current inflexibility and patchy availability across the city. In addition, carers experienced difficulties with finding agency staff experienced in dementia care. According to some carers, the process of accessing support through the Vouchers scheme is laborious and stressful. Some carers would prefer more vouchers for shorter periods: <ul style="list-style-type: none"> <i>‘Just because someone doesn’t have lots of care coming in, doesn’t mean they don’t need other types of support, for example, giving the carer a break for a few hours’.</i> • Respite care provision received a mixed feedback from people with dementia and carers: it worked well for some; however there were difficulties with booking respite |

| The Dementia Care Pathway Standards – Living Well | What matters to local people with dementia & carers |
|---|--|
| | <p>care in advance and some care homes demanded pay from the day of the booking rather than from the day the respite begins. Carers stressed that such costs are impossible to meet. In addition, the lack of support with the provision for cultural differences, e.g. meals and language, was highlighted.</p> <ul style="list-style-type: none"> • Interestingly, there was little reference to care homes specifically at the open community events. However, the difficulties highlighted in relation to information, the low level of skills and competences of the workforce about dementia and access to expert help and advice apply equally to the care home sector and have been raised by individuals who have been in touch about the strategy. The lack of culturally appropriate residential care was raised specifically by the Chinese community. • With regards to issues with transport carers emphasised the need for carers' passes. Often carers have to travel to appointments with people with dementia, yet they may not have their concessionary bus passes which results in incurring significant travel expenses. Good practice around the country mentioned a 'carer's pass' scheme implemented in some localities, e.g. Wales – Plus 1 pass. Travel costs which can be prohibitive at times were cited as a barrier to accessing services in the community – 'getting out and about'. The implementation of the national Blue Badges scheme in Liverpool was said to be delayed. |

Examples of Good Practice –Living Well

The review from the available evidence has highlighted the following examples of good practice.

The Debenham Project

The [Debenham Project](#) is a community-based and community-led voluntary organisation for people with suspected or diagnosed dementia and their families and carers. It provides advice services and support groups that aim to facilitate the maintenance of

social integration and the promotion of independence. The project works closely with professional agencies when required. It is a member of the new Dementia Together Suffolk statutory support service.

The project has been widely [praised by NHS England](#) for its unique approach to caring and supporting people living with dementia and their families and carers. It provides varying levels of support, ranging from straightforward information and advice to active involvement in its groups and services, to about 65% of the estimated number of people living with dementia and their families and carers in its catchment.

Promoting independence and community engagement

The Debenham Project helps people with dementia live independent lives for as long as possible. A range of leisure and community-based activities and support groups are offered. These, together with information and advice, one-to-one support and other services, seek to minimise distress and social isolation for the person living with dementia and their family member or carer. By providing 'something to look forward to', the community groups aim to improve psychological wellbeing, stimulate positive thinking and enhance social integration.

Supporting carers

As well as offering advice and information, the Debenham Project offers carers short-term support. This includes assistance and transport for both the carer and person living with dementia, as well as emotional and practical support including outings, events, afternoon teas, music and games.

Each element of the project fosters social integrity and relationship-building through encouraging positive communication, enjoyment and new coping skills, as well as offering individual support.

Further information

Further information contact Lynden Jackson, Project Chair lynden.jackson@the-debenham-project.org.uk.

ConnectEd, Onside, Worcestershire, England

Onside provides a range of support and advocacy schemes in Worcester, including 'ConnectEd' where experienced mentors provide person-centred activities for people with early onset dementia, diagnosed under the age of 65, as well as support for their carers. Mentors work one-to-one with users, with the aim of stimulating and maintaining their skills and interests, enabling them to engage with their local community and to develop social networks. 'ConnectEd Plus' is now available offering the same support for people diagnosed with dementia over the age of 65.

For more information see: <http://www.onside-advocacy.org.uk/what-we-do/>

Dementia Adventure (UK wide)

Supported holidays and outdoor activities for people living with dementia and carers, families and friends.

<https://dementiaadventure.co.uk/>

Dementia Dogs (Scotland)

Provides assistance dogs and community dogs to increase confidence and reduce social isolation. A collaboration between Alzheimer Scotland and Dogs for Good. <http://www.dementiadog.org/>

Short Breaks – Examples of Good Practice

Surrey GP Carers Prescription Scheme (Incorporating the GP Carer Breaks Service) in partnership with Action for Carers Surrey and Surrey Independent Living Council, England

The Surrey GP Carers Prescription Scheme provides primary healthcare staff with a solution to support carers who need a break. Primary Healthcare staff within GP practices affiliated to the programme can make referrals to a number of organisations and a range of services relevant to carers across Surrey. The support can be provided directly to the carer, or to the person being cared for, to help the carer have a better balance between their caring role and their life outside caring. A Carers Wellbeing Tool is available to staff to help them to informally assess whether a carer is under particular strain and whether a referral to support services may help. Referrals may be made to Social Services for a carer assessment. One off cash payments to help secure a break are also available to carers who are eligible, up to a maximum of £300. This project is provided as part of a broader package of measures to support carers within primary care and as part of the Carers Care Pathway. The project is funded through the Better Care Fund (England based).

TRIO scheme, Person Shaped Support (branches in England and Wales)

Unlike conventional one-to-one or group support services, TRIO works with one (formal) carer and two service users, allowing more opportunities to meet others in the local area with similar interests and make friends through social interaction. This is facilitated by one of the Trio care team. TRIO is provided by trained Shared Lives carers who deliver a flexible service in which carers and their families can receive a break from their caring role and users of the service can be supported to remain independent. There is a branch of TRIO in Conwy. For more information: <http://psspeople.com/how-pss-can-help/get-out-and-about-and-meet-people/who-are-also-living-with-dementia>

Dementia Care Respite, Newcastle, England

Dementia Care, a charity based in Newcastle, offers a range of services to people living with dementia and carers, including

overnight respite support, which is directly linked to their dementia Day Club. The Centre has five en-suite bedrooms, all with accessible toilets and hand basins and two with showers. All rooms are fully accessible and have dementia-friendly furniture and electrically-operated beds. There is a separate bathroom in the Centre with dementia-friendly fittings and an electronic Jacuzzi bath. To assist with people's orientation the same dementia-friendly design is used in the respite rooms as it is in the Day Club, which is on the same site. People are able to use all of the Day Club facilities, including taking meals in the restaurant. However, if people want some quiet time away from Day Club activities, there is a separate lounge and kitchen/dining room in the Respite Centre. This can enable people to have a quiet break away or join in activities with a wider group of people, who may already be known to them. For more information: <http://www.dementiacare.org.uk/services/residentialrespite-care/>

My TIME Liverpool

'[mytime](#)' is deliciously simple!

It connects carers who could benefit from a break from their demanding roles with businesses and organisations offering complementary leisure, cultural and educational activities.

A carer is anyone who cares unpaid for a friend or family member, who due to illness, disability, a mental health problem or an addiction, cannot cope without their support. Carers must live in the specific local authority to benefit from 'mytime' and must be caring for someone over the age of 18.

After receiving funding from The Big Lottery Fund we have been working hard to develop lots of opportunities to offer to carers. We now have a large group of generous organisations who provide activities including theatre tickets, afternoon tea, sports sessions, spa packages, meals and overnight stays.

How it works:

- Organisations and businesses kindly donate a contribution to 'mytime'
- This offer is passed on to carers who are members of 'mytime'
- The 'mytime' team will then liaise with the organisations and businesses to book the carer in
- The carer enjoys the break!

Respality' in Scotland

Respality (Respite + Hospitality) originated in the USA. The hospitality sector 'gift' short breaks, which can be overnight stays, dinner reservations, spa days, beauty treatments – whatever gift the business chooses to donate. The breaks can be made available during quieter periods, when it suits the business. Carers Centres and the Scottish Hospitality sector have worked

together to introduce this scheme to provide short breaks to unpaid carers. Respite is currently available in 14 different Local Authority areas across Scotland. Carers can only access Respite through their local carers centre, and current coverage is being expanded. Businesses wishing to donate a break can do so whether their Local Authority area delivers Respite or not. Personal stories are included on the Respite website, including an example from MindforYou, which provides supported holidays for people living with dementia and their family or friends; they donated a Respite break to allow an Angus couple living with dementia to have a holiday in Grantown-on-Spey. For more information: <https://www.sharedcarescotland.org.uk/respite/>

Using Direct Payments for respite (Wales)

Through our engagement activity, the examples of people using direct payments for respite included: Direct payments for people living with dementia:

- Paying for overnight respite in a place of choice, either on their own or as a family (either in a care home or within the hospitality sector).
- Employing three personal assistant carers who work in rotation, and who operate flexibly to allow the carer to go away for extended periods of time.
- Paying for fuel costs to enable someone to stay with a family member for few days and also paying the family member to provide support, thus giving a break to the main carer.
- Paying for a 'buddy' volunteer for a few hours or days a week, to help support the person living with dementia with what they wanted to do, in or outside of the home.
- Two of the groups who supported our engagement activity (Me Myself & I and Dementia GO) also described how some of their members pay for their support and/or transport through direct payments and group organisers are active in telling members about this option.
- Direct payments for carers: Carers are also entitled to seek support for themselves in the form of a direct payment. One example of this was provided during our engagement work where a carer had used the payment for someone to mow the lawn, which was something he found difficult due to health reasons. It met the outcomes of having a break and sustaining him in his caring role: "Helping with some of the difficult things I was finding to do – things that might alleviate that."

Direct Payments & Citizen Directed Support Scheme, Wales

Direct Payments are payments for people to organise their own care and support and Social Services have a duty to make direct payments available under the Social Services and Well-being (Wales) Act 2014. Direct payments can be used individually or pooled with other people in similar circumstances, which can offer greater 'critical mass' to enable new services to be established, including those that might offer respite. Disability Wales, in partnership with Wales Co-operative Centre, established a Direct

Payments & Citizen Directed Support Scheme, based on evidence of the benefits this can offer⁵³. The scheme provides support for the development of citizen directed co-operatives as a new way to manage Direct Payments. For more information: <http://www.disabilitywales.org/projects/citizen-directedco-operatives-cymru-project/>

Short Breaks Fund, Shared Care Scotland

In Scotland, the Short Breaks Fund provides grants to third sector organisations that support unpaid carers to take a break from their caring role. The fund aims to increase both the range and availability of short breaks across Scotland. Shared Care Scotland operates the Short Breaks Fund on behalf of the National Carers Organisations and the Scottish Government, and the Scottish Government currently funds the Short Breaks Fund on a rolling annual basis. As well as administering the fund, Shared Care Scotland provide:

- a range of support and guidance for funded projects
- a learning platform of 'Short Break Stories'
- information on holiday-type short breaks
- a Short Breaks directory and planner

For more information see: <https://www.sharedcarescotland.org.uk/about-us/>

This programme of work is not dementia specific, but does include dementia short break options

Living Well - Housing & Extra Care Housing Examples of Good Practice

The Orangery extra care scheme – a case study from Optivo

[The Orangery](#) is an extra care scheme for older people in the Sidley neighbourhood of Bexhill on the South coast. It was developed by Amicus Horizon housing association (now Optivo) in partnership with East Sussex County Council and Rother District Council, and opened in April 2016. Key features of the scheme are:

- Fully-accessible apartments and communal areas
- High-quality design and spec
- Care team based on site
- Close to a local high street
- Important role in the local community
- Sustainable restaurant provision

The Orangery was designed to meet the requirements of Lifetime Homes and achieved BREEAM 'Good' accreditation. From the

start, The Orangery has had strong support from the local community... We partnered with a local school who designed the hoarding put up around the site during development and planted a time capsule. Over a year before the scheme opened we also formed an older people's reference group. This was made up of local residents, councillors and members of voluntary/ community groups. They made many decisions such as choice of soft furnishings for communal areas, colour schemes and naming the communal rooms. Just before the scheme opened, this group morphed into the Friends of The Orangery (FoTO). Members organise activities and ensure there's a strong connection between the scheme and the Sidley community. A year on, residents have also formed their own social committee – the 'Amigos'. They're now able to fundraise for events, outings and activities.

[Seafarer's Way](#) is a new-build 38-apartment dementia specialist extra care scheme in Hendon, Sunderland, built next to an existing listed building – The Old Orphanage – which has also been refurbished. The scheme was built by Inclusion Housing, a community interest company. Housing and Care 21 (H&C21) are the managing agent and care service provider. It has been designed to enable people with dementia to live independently in an extra care setting.

Within each apartment there is a range of dementia-friendly equipment and adaptations (to the usual provisions in extra care):

- Coloured toilet seats to enable identification.
- Open kitchen cupboards and shelves so that necessities can be visually identified and traced.
- Sockets and switches with coloured rocker switches to assist with visual identification.
- The “unnecessary” doors in each hallway (cupboards, etc.) have been painted in plain colours to match the walls whilst essential doors – bathroom, bedroom and living space – are wood panelled, with contrasting frames to aid visual identification.
- Ground floor apartments have French doors opening onto a secure garden with winding paths, raised beds and lots of visual connections to the rest of the scheme.

Social and participation opportunities and activities will be available within the range of shared communal areas on the ground floor and in the garden areas. Inclusion Housing will manage the housing scheme and H&C21 will provide the on-site care and support service, which will be on-site 24 hours a day, every day of the year. The scheme is located close to local amenities and community facilities in Hendon. The front of the building will be for community use and will accommodate the East End Community Association, and H&C21 will provide a care shop to enable people in the wider local area to gain access to advice relating to care and support services. Many local people have been employed to work as care staff in the scheme, ensuring that there is a real community involvement, and they are beginning to build a dementia-friendly community in Hendon.

H&C21 provides a minimum of one person awake overnight on every scheme, and usually at least two. This means that whatever their needs, people are assisted to remain within their own home. The extra care model is flexible in that it's not tied to specific times, and there's someone on call at all times for any potential issue. People have the option of as much or as little assistance as

they need, while knowing that they are in a secure environment. The extra care scheme is community-focused, so it's not seen as a locked environment where only people with dementia live. People live in individual apartments, and people living with dementia use all the facilities and the wider services of the larger extra care scheme in the same building. Often, if one member of a couple has dementia and has had to leave home and go to a residential care service, they become extremely distressed, and the carer is also further distressed. There are many examples of people that have been married for 60 years who have been separated. That won't happen within this model. People will still be able to live together with the relevant amount of support.

For further information contact: Victoria Barclay, Regional Director Victoria.barclay@housingandcare21.co.uk
Caire Charlton, Locality Manager Claire.charlton@housingandcare21.co.uk

Fiona Gardens - Trafford

[Fiona Gardens](#) is a new and different extra care scheme in Trafford. This innovation was created by a housing provider, Trafford Housing Trust (THT) and a social care provider, Imagine, Act and Succeed (IAS) and taken as a proposal to the local authority. Our two organisations shared common values and brought our expertise together to work as true partners. THT is the housing provider and IAS the social care provider, working hand in hand to ensure people's wellbeing. People who were interested in moving in were absolutely clear about what they were signing up for: not just a nice apartment but an ethos of true community and long-term sustainable relationships. IAS and THT created the "wellbeing charge", an innovation that relates to the funding of the care at Fiona Gardens. The Local Authority has welcomed the charge as it significantly reduces the cost to them and gives a greater quality of life to the people who live at Fiona Gardens.

The wellbeing charge funds part of the 24/7 on-site care provider. The role and expectations of the support team are key to making Fiona Gardens a great place to live. It was agreed there would be no staffroom and that when staff members were not providing individual support they would have a social presence.

The team at Fiona Gardens use the Five Ways to Wellbeing (www.neweconomics.org/publications/entry/five-ways-to-wellbeing-theevidence) as evidence of improvements in people's health.

We have planned dementia awareness sessions for people who live at Fiona Gardens who do not have dementia. These sessions have also been opened up to family members, staff who work at the restaurant and hairdressers. This is to help people to develop empathy and understanding so that they can interact positively and confidently with the people who have dementia around them.

In addition, other approaches included in this model are:

- ***Circles of Support*** (Community Circles)

- **Progress for Providers** - This tool helps providers to check their progress in delivering personalised support for people living with dementia. IAS and THT are working together using this tool and it helps us focus on the service as a whole rather than from just a housing or care and support perspective.
- **Reablement and Just Enough Support Reablement** means ensuring that people have the right support at the right time.
- **Dignity in Dying** - We are currently planning training in relation to how we support people tactfully and appropriately with this. We will be using the Living well thinking tool.
- **One-page profiles** - All staff and people who have moved in to Fiona Gardens either have or are in the process of developing their one-page profiles. We were very conscious about how we introduced and explained these, but people have been happy to share information and have seen their benefits.
- **Working Together for Change** This is a structured approach to engagement with people using services to review their experiences and determine their priorities for change

For further information contact: Jill Pilkington, Chloe Champion and Ruth Gorman – Imagine, Act and Succeed

jpilkington@imagineactandsucceed.co.uk

ccampion@imagineactandsucceed.co.uk rgorman@imagineactandsucceed.co.uk www.traffordhousingtrust.co.uk Sarah

Bradbury and Rodger Cairns – Trafford Housing Trust Sarah.Bradbury@traffordhousingtrust.co.uk

Rodger.Cairns@traffordhousingtrust.co.uk

Chapter 4 Dying Well

People with dementia have the right to live as well as possible and die with dignity. End-of-life care is part of palliative care, provided as the person nears the end of their life. Care may be provided in hospitals, hospices, care homes or in the person’s own home. A census carried out by the [Dying Matters Coalition \(2009\)](#) found that whilst 68% of the public reported that they are comfortable talking about death, less than a third have actually discussed their wishes around dying.

The following standards are set out as part of the Dementia Care Pathway:

- ‘I am confident my end of life wishes will be respected’
- ‘I can expect a good death’

The following provides a summary of:

- what mattered to local people with dementia and their carers
- how this compared to the new national standards
- what works well and
- areas for improvements

| The Dementia Care Pathway Standards – Dying Well | What matters to local people with dementia & carers |
|--|--|
| <p>End of life care</p> <ul style="list-style-type: none"> • managing physical and psychological needs • supporting social, practical and emotional needs; this should include spiritual or religious support where applicable • supporting the family through the end-of-life period and after the death of the person with dementia. | <p>Some felt that EoLC is largely focused on cancer and heart disease; there is no provision for dementia. Carers’ opinions and voices in determining the best options for EoLC for a family member are often ignored by professionals. In the majority of cases dementia is still not recorded as a cause of death, so the extent of the condition is masked.</p> <p>Areas for improvement</p> <ul style="list-style-type: none"> • There were calls to implement better planning for EoLC services with encouragement of advanced care planning. • More honesty from medics would encourage people to plan what they want at end of life. • Improve post bereavement support for carers as often services come to a stop at the time when they are most needed |

| The Dementia Care Pathway Standards – Dying Well | What matters to local people with dementia & carers |
|---|--|
| <ul style="list-style-type: none"> • End-of-life care can also include support with legal or administrative needs. | <ul style="list-style-type: none"> • Discussions around End of Life Care planning should take place at an early stage and include a range of options including hospice care • Develop a clearer EoLC pathway |

Examples of Good Practice – Dying Well

The review from the available evidence has highlighted the following examples of good practice.

| Dying – Examples of Good Practice |
|---|
| <p><u>Oxleas Advanced Dementia Service</u></p> <p>Oxleas Advanced Dementia Service specialises in looking after people with advanced dementia in their own homes. The people who use the service are typically in their last year of life and have complex mental and physical comorbidities that require a palliative care approach.</p> <p>The service has won an NHS innovation award for its excellent outcomes and was included as a model example of integrated care in a King’s Fund report.</p> <p>Delivering a palliative care plan</p> <p>The service uses a palliative care framework, which focuses on maximising quality of life, minimising risks (such as hospital admissions), reducing carers’ stress, and supporting the person to live and die in their preferred place.</p> <p>As part of this, the named coordinator of care works with the family and carers to develop a holistic palliative care plan that addresses the person’s physical, mental and social care needs, as well as the needs of their family and carer(s). The care plan is regularly reviewed, taking into account the person’s changing needs and that the person living with dementia may have limited capacity.</p> <p>The person’s family and/or carer(s) are well informed of the care plan and possible risks, including what may happen and what they need to do (advance care planning). If there is a crisis, families and carers can contact the care coordinator. A quick (often same day) response occurs, which includes putting in place the required interventions and offering support and reassurance. If the person requires a hospital admission, the care coordinator works with the ward team to try to ensure that the admission is as</p> |

short as possible.

Care coordinators promote **continuity of care** and help people living with dementia and their families and carers to navigate services.

Further information

Further information contact Dr Adrian Treloar, Consultant in Old Age Psychiatry adrian.treloar@oxleas.nhs.uk

Central Manchester Dementia Palliative Care Service

Central Manchester Dementia Palliative Care Service specialises in person-centred inpatient palliative care, to help people living with dementia and their families and carers in their last years, months or days of life. The service prioritises compassion and kindness.

Delivering a palliative care plan

Throughout the progression of the person's dementia, a holistic and flexible approach is applied. The care plan aims to provide as much comfort as possible to the person living with dementia and their family or carer; it follows the Priorities of Care for the Dying Person: – Individualised Care Plan and Communication Record. Regular reviews and updates are made to ensure that the person's psychological, physical, spiritual and religious needs are met.

Following the death of the person, the service provides ongoing support for the family and carers, including onward referrals to bereavement counselling services. To avoid additional distress for family members and carers, the service will also inform all relevant agencies of the person's death including social care, the ambulance service, allied healthcare professionals and any others. Where possible, staff from the service will attend the funeral.

Further information

Further information contact Nicola Johnson, Dementia Nurse Practitioner at Manchester University NHS Foundation Trust nicola.johnson@cmft.nhs.uk or Sue Heatley, Matron/Lead for Palliative and End of Life Care, Manchester University NHS Foundation Trust susan.heatley@cmft.nhs.uk

Compassionate Neighbours

[Compassionate Neighbours](#) is a project developed by St Joseph's Hospice. In collaboration with St Christopher's Hospice and

with the help of Nesta funding it is being rolled out to 7 other hospices across London and the suburbs. Each hospice is at a different stage in development but by the end of 2018 they will have over 750 Compassionate Neighbours.

Compassionate Neighbours are the key stakeholders in the project, it belongs to them and they are guiding the project and how it develops.

What - The role of hospices is to support and enable people to become Compassionate Neighbours in their community. They help them harness their skills and experience to provide social and emotional support to people in their community, helping them live life to the full for as long as they can. Hospices receive referrals for people in the community who would like a Compassionate Neighbour who are then matched with someone who shares similar interests. Compassionate Neighbours are the key stakeholders but the project belongs to everyone who is involved; community members and professionals working in the hospices and beyond, who jointly shape and guide the project and link with other local projects.

They are keen that the project grows and develops as a social movement, connecting with individuals and communities who have traditionally not accessed hospice services because of barriers of language, culture or lifestyle.

For more information, you could contact Carly Attridge, Head of Volunteering, St Joseph's Hospice T: 020 8525 6000 Extn 3017| www.stjh.org.uk

Appendix A – Desktop Review of National Policy and Practice

| Policy | Key Messages |
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| <p>Dementia Finding housing solutions (2014)</p> | <p>Dementia: Finding Housing Solutions, released by the National Housing Federation, the Dementia Services Development Centre, the Housing Learning and Improvement Network and Foundations, shows for the first time how good adapted housing can play a crucial role in supporting people living with dementia. The report found that dementia-friendly homes can help people with dementia live independently for longer, and reduce hospital stays and care home admissions.</p> <p>Housing associations are skilled at building and managing homes suitable for people with a range of care and support needs, and are keen to work with health and wellbeing boards to help people with dementia. All the evidence shows that housing and housing services are pivotal to dementia-friendly communities. Many of the things that people with dementia can do to improve their quality of life and reduce their demand for care are housing-related.</p> <p>The report recommends that commissioners and their local partners work together with housing organisations to enable people with dementia to retain their independence for as long as possible:</p> <ul style="list-style-type: none"> • Clinical commissioning groups should work closely with the housing sector to identify where costs build up in different parts of the care and health system, and to design home based solutions that will relieve these pressures. • Local authorities, housing providers, home improvement agencies and NHS Trusts should work in partnership to develop support services for people with dementia. • Directors of public health should work with housing organisations to increase the diagnosis rates of dementia, building on the existing infrastructure of housing management and support services present within current housing services. |

| Policy | Key Messages |
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| <p>Alzheimer's Society – Dementia UK Report (2014)</p> | <p>Prevalence of Dementia Key findings:</p> <ul style="list-style-type: none"> • The number of people with dementia in the UK is forecast to increase to over 1 million by 2025 and over 2 million by 2051. This is a worse case scenario, under an assumption that there are no public health interventions and changes are driven by an ageing population alone. • There are over 40,000 people with early-onset dementia (onset before the age of 65 years) in the UK. • The total population prevalence of dementia among over 65s is 7.1% (based on 2013 population data). • This equals one in every 79 (1.3%) of the entire UK population, and 1 in every 14 of the population aged 65 years and over • Compared to the 2007 estimates, the current prevalence consensus found there are slightly more people with dementia in the youngest (65 to 69) and oldest (90+) age bands and slightly fewer in the intermediate age groups. <p>Cost of Dementia</p> <ul style="list-style-type: none"> • The total cost of dementia in the UK is £26.3 billion. • The NHS picks up £4.3 billion of the costs and social care £10.3. • Of the £10.3 billion in social care costs, £4.5 billion is attributed to local authority social services for state funded care. The remaining £5.8 billion is what people with dementia and their families pay out annually for help with everyday tasks that are provided by professional care workers, such as washing, dressing and eating. • Two thirds of the cost of dementia (£17.4 billion) is paid by people with dementia and their families, either in unpaid care (11.6 billion) or in paying for private social care. • |
| <p>Prime Minister's challenge on dementia 2020 (2015)</p> | <p>The government's key aspirations are that by 2020 we would wish to see:</p> <ul style="list-style-type: none"> • Improved public awareness and understanding of the factors, which increase the risk of developing dementia and how people can reduce their risk by living more healthily. This should include a new healthy ageing campaign and access to |

| Policy | Key Messages |
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| | <p>tools such as a personalised risk assessment calculator as part of the NHS Health Check.</p> <ul style="list-style-type: none"> • In every part of the country people with dementia having equal access to diagnosis as for other conditions, with an expectation that the national average for an initial assessment should be 6 weeks following a referral from a GP (where clinically appropriate), and that no one should be waiting several months for an initial assessment of dementia. • GPs playing a leading role in ensuring coordination and continuity of care for people with dementia, as part of the existing commitment that from 1 April 2015 everyone will have access to a named GP with overall responsibility and oversight for their care. • Every person diagnosed with dementia having meaningful care following their diagnosis, which supports them and those around them, with meaningful care being in accordance with published National Institute for Health and Care Excellence (NICE) Quality Standards. Effective metrics across the health and care system, including feedback from people with dementia and carers, will enable progress against the standards to be tracked and for information to make publicly available. This care may include for example: <ul style="list-style-type: none"> ○ Receiving information on what post-diagnosis services is available locally and how these can be accessed, through for example an annual ‘information prescription’. ○ Access to relevant advice and support to help and advice on what happens after a diagnosis and the support available through the journey. ○ Carers of people with dementia being made aware of and offered the opportunity for respite, education, training, emotional and psychological support so that they feel able to cope with their caring responsibilities and to have a life alongside caring. • All NHS staff having received training on dementia appropriate to their role. Newly appointed healthcare assistants and social care support workers, including those providing care and support to people with dementia and their carers, having |

| Policy | Key Messages |
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| | <p>undergone training as part of the national implementation of the Care Certificate, with the Care Quality Commission asking for evidence of compliance with the Care Certificate as part of their inspection regime. An expectation that social care providers provide appropriate training to all other relevant staff.</p> <ul style="list-style-type: none"> • All hospitals and care homes meeting agreed criteria to becoming a dementia friendly health and care setting. • Alzheimer’s Society delivering an additional 3 million Dementia Friends in England, with England leading the way in turning Dementia Friends in to a global movement including sharing its learning across the world and learning from others. • Over half of people living in areas that have been recognised as Dementia Friendly Communities, according to the guidance developed by Alzheimer’s Society working with the British Standards Institute². • All businesses encouraged and supported to become dementia friendly, with all industry sectors developing Dementia Friendly Charters and working with business leaders to make individual commitments (especially but not exclusively FTSE 500 companies). All employers with formal induction programmes invited to include dementia awareness training within these programmes. • National and local government taking a leadership role with all government departments and public sector organisations becoming dementia friendly and all tiers of local government being part of a local Dementia Action Alliance • Dementia research as a career opportunity of choice with the UK being the best place for Dementia Research through a partnership between patients, researchers, funders and society. • Funding for dementia research on track to be doubled by 2025. <ul style="list-style-type: none"> ○ An international dementia institute established in England. ○ Increased investment in dementia research from the pharmaceutical, biotech devices and diagnostics sectors, including from small and medium enterprises (SMEs), supported by new partnerships between universities, research charities, the NHS and the private sector. This would bring world class facilities, infrastructure, drive capacity building and speed up discovery |

| Policy | Key Messages |
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| | <p>and implementation.</p> <ul style="list-style-type: none"> ○ Cures or disease modifying therapies on track to exist by 2025, their development accelerated by an international framework for dementia research, enabling closer collaboration and cooperation between researchers on the use of research resources – including cohorts and databases around the world. ○ More research made readily available to inform effective service models and the development of an effective pathway to enable interventions to be implemented across the health and care sectors. ○ Open access to all public funded research publications, with other research funders being encouraged to do the same. ○ Increased numbers of people with dementia participating in research, with 25 per cent of people diagnosed with dementia registered on Join Dementia Research and 10 per cent participating in research, up from the current baseline of 4.5 per cent. |
| <p>The Mental Health Foundation Dementia, rights, and the social model of disability - A new direction for policy and practice? (2015)</p> | <p>Work undertaken by the Mental Health Foundation in 2015³² highlights the case for taking a social model and rights based approach. Put simply, the prevailing current ‘medical’ model focuses on the losses and deficits resulting from a diagnosis of dementia and is often experienced as counter intuitive to the aspiration of ‘living well’ with dementia. The following summary provides the key elements of both models when applied to people affected by dementia.</p> <p>Medical Model</p> <ul style="list-style-type: none"> • The problem is contained within the individual; dementia is about deficits –what’s the cure? • A person with dementia is not involved in decisions: decisions are made for them • A person with dementia has no responsibilities, no control and is disempowered • People with dementia are charity cases in need of sympathy; they are victims and are objectified • People with dementia are passive dependent |

| Policy | Key Messages |
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| | <p>Social Model</p> <ul style="list-style-type: none"> • Social, attitudinal and architectural environments are the barriers to an individual's participation • A person with dementia is at the centre of the decision-making process (and is supported in this way) • A person with dementia is responsible, has control and is empowered and self-determining (facilitated by the appropriate support) • People with dementia have human rights, are deserving of dignity and respect, and are active subjects • People with dementia are active citizens <p>Implementing a social model requires a significant change in relationships between those providing support (at individual, system and organisational level) and those receiving care and support. It requires a shift in the balance of power in these relationships, such that people affected by dementia can exercise their rights of freedom, respect, equality, dignity and autonomy. The guidance recommends that the following PANEL principles should direct the relationships at all levels:</p> <ul style="list-style-type: none"> • Participation - Everyone has the right to participate in decisions that affect their lives • Accountability - Effective monitoring of human rights standards and remedies for breaches • Non-discrimination and equality - All forms of discrimination in the realisation of rights are prohibited, prevented and eliminated with priority given to the most vulnerable • Empowerment - Individuals and communities should understand their rights and be supported to participate in the development of policy and practices that affect their lives • Legality of rights - Recognition of rights that are legally enforceable entitlements (linked to national and international law). |
| Challenge on dementia 2020: | This implementation plan was developed with key strategic partners and critically there |

| Policy | Key Messages |
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| <p>implementation plan (2016)</p> | <p>was also extensive engagement with people with dementia and carers, in partnership with Dementia UK, Alzheimer's Society and the DEEP and Tide networks. It sets out priority actions, and the organisation responsible, across 4 themes:</p> <ul style="list-style-type: none"> • risk reduction • health and care • awareness and social action • research <p>This implementation plan around two clear phases:</p> <ul style="list-style-type: none"> • Up to 2018 – this covers the immediate actions both Government and delivery partners will take over the next 12-18 months to improve dementia care and support, awareness and research. Funding for these is already set, and the Implementation Plan describes in more detail how these actions will be achieved. • 2018-2020 this covers longer term actions that will deliver all of the 2020 Challenge commitments. The actions included in this phase are indicative and in less detail. They may need to be altered or amended in future years to take into account funding allocations, emerging and planned research into science and medicine, and best practice in both clinical and social care. |
| <p>The Care Act (2014) and associated updates /amendments (2018)</p> | <p>Carers and prevention – some edited highlights in relation to assessment, support and carer advocacy</p> <p>Section 2.16 is focused on carers - Carers play a significant role in preventing the needs for care and support for the people they care for, which is why it is important that local authorities consider preventing carers from developing needs for care and support themselves. There may be specific interventions for carers that prevent, reduce or delay the need for carers' support. These interventions may differ from those for people without caring responsibilities. Examples of services, facilities or resources that could contribute to preventing, delaying or reducing the needs of carers may include but is not limited to those which help carers to:</p> <ul style="list-style-type: none"> • care effectively and safely – both for themselves and the person they are supporting, |

| Policy | Key Messages |
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| | <p>for example, timely interventions or advice on moving and handling safely or avoiding falls in the home, or training for carers to feel confident performing basic care tasks</p> <ul style="list-style-type: none"> • look after their own physical and mental health and wellbeing, including developing coping mechanisms • make use of IT and other technology • make choices about their own lives, for example managing their caring role and paid employment • find support and services available in their area • access the advice, information and support they need including information and advice on welfare benefits and other financial information and about entitlement to carers' assessments (see chapter 6) <p>2.17 Carers Assessment - As with the people they care for, the duty to prevent carers from developing needs for support is distinct from the duty to meet their eligible needs (see chapter 6). While a person's eligible needs may be met through universal preventative services, this will be an individual response following a needs or carers assessment. Local authorities cannot fulfil their universal prevention duty in relation to carers simply by meeting eligible needs, and nor would universal preventative services always be an appropriate way of for meeting carers' eligible needs.</p> <p>2.20 Developing resilience and promoting individual strength. In developing and delivering preventative approaches to care and support, local authorities should ensure that individuals are not seen as passive recipients of support services, but <i>are able to design care and support based around achievement of their goals.</i></p> <p>Section 3 – Carers needs information / support & access to Advocacy - In providing information and advice, local authorities must recognise and respond to the specific requirements that carers have for both general and personal information and advice. <i>A carer's need for information and advice may be separate and distinct from information and advice for the person they are caring for.</i> These distinct needs may be covered together, in a similar manner to the local authority combining an assessment of a person needing care and support with a carer's assessment (where both the</p> |

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| | <p>individuals concerned agree) (see chapter 6 on assessments), but may be more appropriately addressed separately. This may include information and advice on:</p> <ul style="list-style-type: none"> • breaks from caring • the health and wellbeing of carers themselves • caring and advice on wider family relationships • carers' financial and legal issues • caring and employment • caring and education • a carer's need for advocacy |
| <p>National Dementia Action Alliance Declaration – Dementia Statements (2017)</p> | <p>The person with dementia is at the centre of these statements. They represent everyone living with any type of dementia regardless of age, stage or severity.</p> <p>The “we” used in these statements encompasses people with dementia, their carers, their families, and everyone else affected by dementia.</p> <p>These rights are enshrined in the Equality Act, Mental Capacity legislation, Health and care legislation and International Human Rights law.</p> <ul style="list-style-type: none"> • We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it. • We have the right to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness. • We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live. |

| Policy | Key Messages |
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| | <ul style="list-style-type: none"> • We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future. • We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part. |
| <p><u>BEYOND THE FRONT DOOR</u>: What 'home' means to people with dementia and their carers Implications for policy and practice (2017)</p> | <p>A core commitment of the Prime Minister's Challenge on Dementia 2020 is to enable people living with dementia to be supported to live independently in their own homes for as long as they are comfortable and safe to do so. It is recognised that this will include adaptations to accommodation and exploring housing options as well as social care support to preserve independent living for as long as possible. In the Challenge's Implementation Plan, there is a commitment that the Department of Health (DH) will work closely with the Life Story Network (LSN) to focus on older people and people with dementia who live in social housing, to ensure they are supported to live in their homes for longer with a focus on independent living, avoiding costly crisis care and emergency admission to hospital as well as delaying admission to residential care.</p> <p>The aim of this project was to:</p> <ul style="list-style-type: none"> • Explore issues relating to the concept of 'home' to better understand their importance in relation to the sense of identity and wellbeing for people living with dementia, in order to improve post-diagnostic and multi-agency support. <p>The objectives of this project are to:</p> <ul style="list-style-type: none"> • Gain greater insight into the understanding of 'home' for people living with dementia • Develop awareness amongst professionals, particularly housing support staff, charged with supporting people living with dementia to continue to live at home • Enable better transitions to take place if someone living with dementia has to move <ul style="list-style-type: none"> • Contribute to the implementation of compassionate relationship-centered care and support • Develop a set of products that support staff in working with people affected by dementia across the range of agencies (housing, NHS Trusts, NHS and local authority commissioners), with responsibility for both commissioning and providing |

| Policy | Key Messages |
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| | <p>meaningful post diagnostic care and support.</p> <p>Recommendations included:</p> <ul style="list-style-type: none"> • This report should be distributed within NHS England, Public Health England, ADASS, the LGA, Dementia and Housing Working Group, the Carers Trust and other key voluntary sector organisations to highlight the importance of ‘home’ and its relationship with identity and well-being, in particular for older people, people with dementia and their carers • After a diagnosis of dementia, support programmes should include opportunities to consider people’s homes, their housing needs and planning for the future, alongside financial planning, making a will and having a Lasting Power of Attorney for example • NHS and social care assessors should include discussions about what home means to individuals to inform their assessments, care and support planning and risk assessments • Registered Social Landlords should review the information that they produce about the types of housing they offer and ensure that these are described in straightforward language, The ‘Social care, health and housing are three legs of a stool. Underinvest in one and the stool can only wobble on two legs for so long ...’ Watts, (2016). They should also set out what potential residents can expect in sheltered housing, extra care housing and group living schemes for example, and should consider a “Settling-in Pack” for new residents. Their information should ensure that people from particular communities, e.g. LGBT people, those from minority ethnic groups and people without children, feel welcomed and that their needs are of equal importance • Registered Social Landlords should review their processes in relation to - applications for accommodation, making offers, signing tenancies, induction into properties and reviews of tenancies - to ensure that all options are explored and explained fully. This should smooth transitions and mitigate the distress associated with having to move, minimise the risk of moving into unsuitable accommodation and identify emerging problems as early as possible. • Health and social care commissioners should be encouraged to start ‘commissioning |

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| | <p>for home.’ This should make explicit the importance of home in relation to our identities and well-being</p> <ul style="list-style-type: none"> • Registered Social Landlords should include in their workforce development plans bespoke training on <ul style="list-style-type: none"> ○ the impact of dementia on people who have been diagnosed ○ the impact on their relatives and friends and ○ the ways in which housing professionals can support people to live well with dementia • Registered Social Landlords should be included as equal partners in planning forums for older people, people with dementia and carers • NHS bodies, local authorities and Registered Social Landlords should ensure that older people, people with dementia and carers are involved in strategy development and service design, including housing developments • Commissioners, NHS Trusts, local authorities, social care providers and Registered Social Landlords should satisfy themselves that the services they are commissioning and providing are compliant with the Equalities Act and the Human Rights Act, particularly in relation to people with dementia. They should make sure that policies in relation to adaptations, for example, do not inadvertently discriminate against people with dementia. |
| <p>My future wishes Advance Care Planning (ACP) for people with dementia in all care settings (2018)</p> | <p>Advance care planning (ACP) is fundamental for everyone living with dementia. This guidance provides the basis for delivering person-centred end of life care in line with the wishes and preferences of the individual;</p> <ul style="list-style-type: none"> • Enables a record of the individual’s wishes and preferences, which guides the person’s care when they have lost mental capacity and provides crucial support for families and carers • Offers ongoing vital opportunities to enhance the choice and control an individual has over their treatment and care needs / preferences throughout their care journey. |

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| | <p>It provides a simple framework for ACP</p> <ul style="list-style-type: none"> • An ongoing continuous process of open, honest and sensitive conversations evolving over time (with regular reviews), with the person diagnosed with dementia and those important to them (e.g. carers / family) • An inclusive, personalised, multifaceted approach that includes the person diagnosed with dementia and those important to them. • Continuity in the healthcare journey. An ACP conversation can be initiated or continued by any one of the ACP competent multidisciplinary team • Key priorities of the person that need to be explored. For example the person's wishes, choices and preferences, both personal and for care, emergency plans. • Shared Decision Making • Use of consistent / standardised ACP templates, accessible language usage and terminology and support to address language or other communication difficulties. • Initiate; Assess & Check. |
| <p>Carers Action Plan 2018 – 2020</p> | <p>The plan sets out the cross-government programme of work to support carers over the next 2 years.</p> <p>It is structured around the following themes:</p> <ul style="list-style-type: none"> • services and systems that work for carers • employment and financial wellbeing • Supporting young carers • recognising and supporting carers in the wider community and society • building research and evidence to improve outcomes for carers |
| <p>After a diagnosis of dementia: what to expect from health and care services: A guide to the support people should get from local services in England if they or someone they know have been diagnosed with</p> | <p>This guide has been produced by the National Programme Board for Dementia and sets out what post diagnostic support you should expect. It covers the following areas:</p> <ul style="list-style-type: none"> • Your care plan • A named person to support you • Help with day-to-day activities • Help for the people who care for you |

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| dementia (2018). | <ul style="list-style-type: none"> • Getting medical treatment for dementia symptoms • Treatment for other medical conditions • How other health and care staff can help • If you need to stay in hospital • Making decisions about your future • Taking part in research • Telling people what you think about your care • Local organisations that can help • Care in the later stages • Compassionate care at the end of your life • Where to go for more information |
| APPG Inquiry - dementia and disability (2018) | <p>The All-Party Parliamentary Group on Dementia is holding an inquiry into dementia and disability.</p> <p>Despite dementia falling within the legal definition of ‘disability’ within domestic and international law, it may not necessarily be viewed in this way by the public, organisations and people affected by dementia. The APPG is looking at how people view dementia and what it means to identify dementia as a disability.</p> <p>It is evident that people with dementia face a number of challenges in having their rights upheld across all areas of life, including accessing healthcare services, exercising their right to vote or being able to live independently in the community. This can partly be because it is considered a ‘hidden’ or ‘invisible’ disability. The APPG is investigating the barriers that people with dementia face in having their rights met and the impact of this on daily life.</p> <p>The APPG launched a call for evidence for this inquiry, which local people with dementia and carers contributed to. See the report produced by Tide in response to this inquiry.</p> |

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| | <p>The responses are now being analysed and will feed into a report due to be published in late 2018.</p> |
| <p>Dementia Friendly Hospital Charter 2018</p> | <p>The Dementia-Friendly Hospital Charter was launched in 2015 as the second phase of the Right Care initiative. The charter outlines the high level principles that a dementia-friendly hospital should provide, together with notes for self-assessment and recommended actions they could take to fulfil them. One of the key aspirations of the Prime Minister's Challenge on Dementia 2020 is to create dementia friendly hospitals. The purpose of the Charter to:</p> <ul style="list-style-type: none"> • Act as a short, accessible and visible statement of the principles that contribute to a dementia friendly hospital • Provide a minimum set of standards that focus on the needs of people with dementia and their families/carers and what they can rely on when they access a dementia-friendly hospital • Build on the foundation offered by the Royal College of Nursing's Staff, partnership, Assessment, Care and Environment (SPACE) principles by including the latest developments and signposting resources that hospitals can use to embed dementia-friendly principles in their organisations • Offer a framework to assist hospitals in their self-assessment against the dementia-friendly principles and develop and update an NDAA Action plan on the website <p>It focuses on a number of key themes including:</p> <ul style="list-style-type: none"> • Staffing • Partnership • Assessments • Care • Environment • Governance and • Volunteering |

Appendix B - Mapping against Liverpool Commissioning Strategy for Dementia 2014- 2016 and the Progress Summary Report 2016

| Key area | 2014 | 2016 | Priorities for refreshed strategy |
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| <p>1. Increased awareness of dementia and work towards Liverpool becoming recognised as dementia friendly city</p> | <ul style="list-style-type: none"> • A pledge to join the local Liverpool Dementia Action Alliance to promote awareness and understanding of dementia • To reduce stigma across all sectors including health, care, social and business • To work with the DAA and its 30 members to increase the number of people in the city who are 'dementia aware' including 'Dementia Friends' | <ul style="list-style-type: none"> • Continuing involvement of the City Council and the CCG in Liverpool DAA Coordinating group • DAA's membership increases to 46 organisations • DAA signed up to the national recognition process to work towards becoming recognised as a 'dementia friendly community' • Work ongoing in the areas of the promotion of dementia awareness across all sectors through participation in events for businesses, and transport, delivering training, attending and facilitating conferences • Focus on continuing work around raising awareness, reducing stigma and changing cultural beliefs about dementia in BAME communities | <ul style="list-style-type: none"> • Continue to fund BAME Dementia Champions project (funding stopped in 2017). Recommendations outlined in the 'Dementia does not discriminate' (2013) report provide a useful guide to service delivery tailored to the needs of people with dementia from BAME communities⁵ • Monitor Dementia Awareness training for quality and consistency • Address issues around carers' travel options through the introduction of carers' travel passes and the implementation of the revised Blue Badges scheme • Focus on the intergeneration awareness raising by |

⁵ All Party Parliamentary Group on Dementia, Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities (2013)

| Key area | 2014 | 2016 | Priorities for refreshed strategy |
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| | | | <ul style="list-style-type: none"> engaging with schools • Create opportunities for local peer support groups to develop • Continue to develop SURF – consider whether a separate group (advisory) for carers would be helpful. |
| 2. Timely identification and diagnosis within targeted risk groups | <ul style="list-style-type: none"> • A pledge to implement a process to review those groups at a higher risk of developing dementia • To expand locally the national scheme of funding for GPs to regularly review specific groups of patients who are considered high risk of developing dementia • Ensure that carers are identified at the key contact points with health and care services and that | <ul style="list-style-type: none"> • The national scheme to identify and review people at risk of developing dementia extended to include delirium (aged 75+) and mild cognitive impairment • Work continued on other schemes whose aim was to ensure people who were at risk of developing dementia had the opportunity to receive screening (e.g. National Dementia CQUIN for 2015/16 for acute hospitals to find) • BAME dementia champions service funded to work with 5 cultural communities - Chinese Wellbeing, Kensington Older People’s Network, African Elders Association, Merseyside Yemeni Association, | <ul style="list-style-type: none"> • Identify and address gaps in delivering timely diagnosis to younger people with dementia • At diagnosis offer information on dementia and post-diagnostic support for people with dementia and carers, including carer’s assessment • Provide funding support to services and projects working with BAME cultural and faith communities; BME Dementia Champions initiative model previously funded and evaluated can be adopted to continue promoting awareness of dementia and facilitating access into primary |

| Key area | 2014 | 2016 | Priorities for refreshed strategy |
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| | <p>carers are offered annual assessment for care support</p> <ul style="list-style-type: none"> • Work with community organisations to develop a proposal for service provision supporting the awareness and understanding of dementia amongst BAME groups across the city | <p>Somali Elders to increase awareness and to support people through the diagnostic process</p> | <p>and secondary health care among BAME populations (Abimbola, D (2014) BME Dementia Champions Project: An Evaluation Report)</p> |
| <p>3. Delivering improvements to dementia care through participation and engagement</p> | <ul style="list-style-type: none"> • Service redesign will be undertaken with service users to ensure that changes made reflect the needs of people with dementia. This will be achieved through a meaningful engagement with the Service User Reference Forum (SURF) chaired and co-chaired by people living with dementia and current and former carers | <ul style="list-style-type: none"> • The SURF group continues to meet monthly and now includes representatives from Liverpool Clinical Commissioning Group, Liverpool City Council, Mersey Care NHS Trust and the Alzheimer's Society. Other organisations request attendance. The group's expert advice has become integral to service development and delivery | <ul style="list-style-type: none"> • Continue to work with SURF and create further opportunities for engaging people with dementia and carers as experts by experience in service design, delivery and research • Ensure consistent attendance at SURF by city council and CCG representatives • Draw on the expertise of good practice models that exist across the city: Healthiness, Everton in the Community, Carers Centre, House of Memories. • Maintain what is currently available and protect successful initiatives from budget cuts |

| Key area | 2014 | 2016 | Priorities for refreshed strategy |
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| 4. Establish joined up working and care between GP and Specialist Dementia services | <ul style="list-style-type: none"> • Establish new working practices between GPs and specialist consultants working in secondary care in order to achieve greater flexibility and ease of access for people living with dementia to receive specialist care when needed | <ul style="list-style-type: none"> • Dementia Clinical Network established with the aim to ensure equity of access to post diagnostic support • Work is under way with clinicians to establish a shared model with a single access point for post diagnostic support | <ul style="list-style-type: none"> • Ensure that the members of Dementia Clinical Network continue to align their processes and to deliver joined up care • Consider establishing 'Well Carer' clinics in practices across the city to begin addressing mental and physical health needs of carers • Establish a 'One Stop Shop' for dementia services operating as a single access point for post diagnostic support • Establish a 24 hour crisis line with CPN support |
| 5. To provide access to high quality post diagnostic support | <ul style="list-style-type: none"> • Commission a comprehensive range of quality assured, clinically evidenced post diagnostic support • Provide information both pre and post diagnosis to everyone who accesses dementia services • Provide tailored support to allow people to live well with dementia by | <ul style="list-style-type: none"> • Extra investment secured for increasing the capacity of services to deliver increased provision of timely, city-wide post diagnostic support • A structured course run as a part of a post diagnostic support group offered following a diagnosis, with significant progress made in the number of these groups run for people with dementia and carers and the locations of these groups • Aligned information sharing processes and consistent quality of information achieved as a result of the clinical network establishment | <ul style="list-style-type: none"> • Address gaps in service provision to individuals with dementia without carers, including information, care planning, activities to provide stimulation and reduce/avoid isolation • Funding should be provided for people with complex or exceptional needs to prevent them being excluded from day services • Increase the number of Care Navigators available across the city • Improve Direct Payments system |

| Key area | 2014 | 2016 | Priorities for refreshed strategy |
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| | <p>accessing appropriate services, as identified by a personalised care plan, regardless of type of dementia diagnosed, age, ethnicity or address</p> | <ul style="list-style-type: none"> • An information leaflet coproduced with people living with dementia and carers and a more substantial information pack about existing services and support are now available • Care Navigators service available to those who choose not to attend the post diagnostic support groups • Information on post diagnostic support is available through a range of channels, including via care navigators, dementia support workers, Liverpool Service User Forum and staff in the CMHT and on Livewell Liverpool www.livewellliverpool.info • Assistive technology pilots with people living with dementia and carers and are currently being run aiming to test equipment to explore the potential it may have for reducing risk and promoting independence. • Consultation with carers is under way to develop a new integrated Carers Strategy | <p>making it easier to access for all</p> <ul style="list-style-type: none"> • Improve access to information about assistive technology making it available in a range of formats as not everyone has access to the Internet • Review and improve carers voucher scheme making it more flexible and accessible in all areas of the city • Commission Admiral Nurses service in Liverpool • Implement recommendations for respite service provision outlined in LCC report (2016) • Provide comprehensive advice on the quality of care homes in the city • Promote advanced care planning and support people with dementia and carers to access advice on this |
| <p>6. To provide good hospital care for people with</p> | <ul style="list-style-type: none"> • Continue to work with our hospitals, mental health and community trusts to | <ul style="list-style-type: none"> • All main providers of hospital care are developing dementia training programmes to ensure all their staff have a level of dementia awareness | <ul style="list-style-type: none"> • Develop and offer a high quality staff training based on a blended approach • Use Dementia Friends awareness |

| Key area | 2014 | 2016 | Priorities for refreshed strategy |
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| dementia | improve inpatient care for people with dementia, driven by the national dementia CQUIN | <ul style="list-style-type: none"> • The acute hospitals have identified lead clinicians for dementia • Some of the strategies being used involve people with dementia having a special care plan (e.g. This is Me) | <p>as an add-on, not as a main training programme</p> <ul style="list-style-type: none"> • Offer other opportunities for staff to improve knowledge and competencies around dementia care to drive the change in culture and in attitudes to people with dementia and carers |
| 7. To stimulate housing provision that is supporting of people with long term conditions including dementia | <ul style="list-style-type: none"> • To ensure that housing needs of people with dementia are included within the remit of Health, Care and Housing Sub-Group of the Health & Wellbeing Board • Monitor the effectiveness of the new Extra Care Housing contract in meeting the needs of people with dementia. | <ul style="list-style-type: none"> • Through a piece of work with the Liverpool Dementia Action Alliance and a Department of Health funded Project led by the Life Story Network there is growing understanding about the need to readily advise people with dementia and carers regarding possible housing options available to them. • The work of the DAA is aiming to influence architects and builders to incorporate dementia friendly design principles into new schemes that they are commissioned to build and design. | <ul style="list-style-type: none"> • Provide information to people with dementia and carers who chose to stay in own home about options available to them, such as grant applications for home adaptations • Offer a range of assistive technology equipment designed to meet specific needs of people with dementia (e.g. bathroom equipment and adaptations in a variety of colours not in white). • Improve telecare systems to enable people to take advantage of the Internet of Things (Blood and Associates (2017) Housing and Support for Older People in Liverpool) |