



Refresh of Liverpool's Joint Dementia Strategy

Report, Recommendations and Supplementary Documents

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Revised 1 March 2019



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Acknowledgements

Thank you to Liverpool city council and Liverpool CCG for the opportunity to lead this important piece of work and meet so many amazing people with dementia, carers, staff and volunteers in the city who are all keen to see it become the best place to live with dementia in the UK. We would also like to thank the Service Users Reference Forum, Tide – Together in Dementia Every Day, the Life Story Network CIC and Chinese Well-Being for their particular contributions to the work; Pauline Burke for administrative support; Natalie Markham for a clear steer throughout; Margaret Flynn for editorial advice; Christina Berry Moorcroft for formatting the report; and all those who contributed their time, insights and ideas along the way.

Report

Who we are

Dementia Action Liverpool (DAL) is a not-for-profit limited company established in 2017 to manage the business functions of the Liverpool Dementia Action Alliance (LDAA)¹ which is a collaborative of member organisations. The aims of the two bodies are identical. DAL's three Directors are Ruth Eley, LDAA chair; Jack Coutts, vice-chair; and Lynne James, representative of SURF (Service Users Reference Forum).

What we were asked to do

Dementia Action Liverpool was invited to submit a proposal during March 2018 to carry out the refresh of Liverpool city council (LCC) and Liverpool CCG's (LCCG) joint dementia strategy of 2014-2018, to generate a new strategy for 2019-2024. The specification for the work suggested the following key steps:

- Review progress against current strategy
- Identify achievements, areas of good practice, opportunities for collaboration and outstanding actions

¹ Which does not exist as a legal body and therefore cannot enter into a contract

- In partnership with Public Health, LCC and LCCG, update the 2016 needs analysis
- Conduct a “horizon scanning exercise” so that key national and local policies, reviews and audits, opportunities are captured to give an accurate picture of the current and future operating environment
- Establish the “As Is” picture of current dementia services offered across the whole health, housing and social care economy from prevention to complex needs and End of Life
- Prepare a stakeholder map and stakeholder management plan – Clinical Operations Network to advise on the individuals/ groups who should be included
- Co-ordinate and facilitate engagement with people living with dementia, their carers, partners across health and social care, and wider partners in the community, voluntary, faith, cultural, academic sectors to explore key issues and inform the strategic priorities.
- Produce a strategy and associated implementation and finance/investment plan that sets out the “To Be” vision and ambition for dementia services in Liverpool.

Liverpool had already established a number of key priorities for the refreshed strategy based on preliminary stakeholder feedback which included reflections on progress to date against the existing strategy (see Appendix 1). DAL’s proposal was accepted and work began in April 2018 (see Appendix 2).

There were two starting points - the content of the 2014-2018 joint strategy (see Appendix 3) and the known facts concerning people with dementia in Liverpool.

Dementia in Liverpool

At the time of writing some of the data requested had still not been made available. This includes Delayed Transfers of Care data so we have been unable to examine this issue in any detail.

In 2016-17 there were 3,542 people diagnosed with dementia recorded on practice registers; of these, 858 were newly diagnosed during this period. 3,401 were over 65. 173 people under 65 were on practice registers.² The number of people diagnosed with dementia is expected to rise to 5663 in 2021.³ The diagnostic rate is currently 69.7%, above the national target of 66.7% but less than the 76.5% achieved in 2015 and 78% in the previous year; this means that there are an

² Public Health Profiles: Dementia profile for Liverpool <https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia/data#page/1/gid/1938132811/pat/6/par/E12000002/ati/102/are/E08000012> accessed 140918

³ Progress on Liverpool dementia strategy (2016), Liverpool CCG

estimated 31% of people living with dementia who do not have a diagnosis. Prevalence rates in GP practices in November 2018 varied from 24% to 0.86%. The 'One Liverpool' plan⁴ includes the unambitious target of maintaining the diagnostic rate at 70% - the only mention of dementia throughout the entire document.

In the current strategy, Liverpool CCG undertook to update and improve its data relating to people from BAME groups diagnosed with dementia. No further work has been done. The April 2017 data from practice registers is unreliable as 26.6% of people diagnosed had no ethnicity stated. Of those where ethnicity was stated, 96% were White British/White Irish or other White, with only 4% stated as non-White ethnicity. It is unclear whether people were unwilling to state their ethnicity or practice staff neither sought nor recorded the information.

Other Liverpool data⁵⁶⁷ relevant to the local strategy tells us:

- Only 23.7% of adult carers had as much social contact as they would like, compared with 35.5% in England
- Carers of people living with dementia reported a lower quality of life score (6.8) than the national score of 7.6
- 65.8% of people with a diagnosis of dementia used in-patient services, compared with 55.1% in England as a whole
- The rate of emergency inpatient admissions for people where dementia was mentioned was 4849 per 100,000, compared with 3482 nationally
- 2.5% of Direct Payment recipients are people requiring support with memory or cognition – the same % as in 2014
- Of Liverpool City Council's total gross expenditure on 'Support with memory or cognition' in 2016-17, 79% was spent on residential or nursing home care, 9.8% on home care, 7.4% on short term care to maximise independence, 2% on Direct Payments and 1.1% on supported living
- 31% of residential and nursing care beds for people over 65 were rated as 'good' or 'outstanding', compared with 59.7% for England
- 65.1% of people with dementia died in their usual place of residence, compared with 67.9% for England and
- 33.5% of people with dementia died in hospital and 10.5% at home, compared with 30.9% and 9.7% in England as a whole.

Appendix 4 sets out the findings. In summary, these revealed that:

- Significant progress has been made in terms of implementing the 2014-2018 strategy, in particular: initial increases in the diagnostic rate; the establishment of the clinical network; the standard offer of post-diagnostic support across the

⁴ One Liverpool: 2018-21 The Long and Winding Road to a Healthier Life (2018) Liverpool CCG

⁵ Public Health Profiles: Dementia profile for Liverpool, as above

⁶ Adult Social Care Workforce return 2016-17, Liverpool City Council

⁷ Adult Social Care Workforce return 2016-17, Liverpool City Council

city; and the introduction of dementia care navigators. Awareness of dementia has improved and the city has a strong and active Dementia Action Alliance that brings together almost 70 organisations to help make it more dementia-friendly. SURF is well established and, along with other peer groups, it is highly valued.

- However, some services have diminished since the current strategy was launched. The diagnostic rate is now falling and is below even the modest target in the One Liverpool strategy. Funding cuts to the voluntary sector have resulted in severe reductions to the BAME Champions service, which has disappeared completely from the Somali and Yemeni communities, and the withdrawal of services provided by the Alzheimers Society in Liverpool. Although some have continued through voluntary effort, gaps remain. The carers voucher scheme is not fit for purpose in meeting the needs of carers of people with dementia and short breaks in residential care are unreliable and difficult to access.
- We know from the data that the carers of people living with dementia in Liverpool have more restricted social lives and report a lower quality of life score than in the North West regional and nationally. There is a higher rate of inpatient use and of emergency admissions where a diagnosis of dementia is recorded than the regional and national comparators. Only 1/3 care homes achieve 'outstanding' or 'good' quality ratings compared with 50% in the region and almost double the number nationally.
- No progress has been made in developing an effective out of hours crisis service available over 24 hours, that can respond to the needs of people living at home and their carers as well as service providers such as residential or home care.
- There is a strong desire from community, voluntary and independent sector providers to be seen as part of the solution and treated as equal partners by the LCCG and LCC. Given the gaps in provision that this work has confirmed, there is an urgent need to bring people to the table to seek out potential solutions. Involving people with dementia and carers in this process is essential to ensure that lived experiences shape commissioning intentions and decisions.
- Dementia is the biggest challenge facing the city in terms of numbers of people affected, needs and costs. It is currently the largest cause of death and is a public health issue as significant for the city's population as 'flu, smoking, heart disease and cancer. This requires concerted action by all public bodies.

Recommendations

1. We propose the following overarching aim for the 2019-2024 strategy:

To enable people with dementia and their carers to live as well as they can with the condition, at whatever stage of the illness and wherever they live.

2. We propose the following strategic objectives:
 - i. Continue to raise awareness and understanding of dementia, including all communities, providing information in appropriate languages and formats and working with Liverpool DAA to reach beyond the health and care sector
 - ii. Increase timely and appropriate diagnosis year on year, aiming for 80% by 2024
 - iii. Commission high quality post-diagnostic support that meets the need of particular groups and communities, includes equitable access to dementia care navigators and increases the take-up of the initial offer of post-diagnostic support from 60% to 80% year on year to 2024
 - iv. Develop options to deliver access to crisis support over 24 hours
 - v. Develop options to deliver short breaks that offer choice and provide positive experiences for people with dementia and their carers
 - vi. Ensure that people with dementia and carers are involved in planning and service re-design
 - vii. Use the opportunities created by the commissioning of the three residential hubs to work with the community, voluntary and independent sectors to make the best use of experience and expertise to develop solutions to meet gaps in current provision
 - viii. Make the best use of community assets⁸, ensuring that social prescribing includes people with dementia and carers, and explore the potential for developing 'Meeting Centres' in Liverpool
 - ix. Ensure strategic leadership from the CCG and the City Council at senior manager level to champion and implement this strategy

See Appendix 6 for draft preliminary implementation plan.

⁸ These include **organisations, people, partnerships, facilities, funding, policies, regulations, and a community's collective experience**. Any positive aspect of the community is an asset that can be leveraged to develop effective solutions.

Appendix 1

The Backdrop – Key priorities already identified for the strategy refresh

Liverpool had already established a number of key priorities for the refreshed strategy based on initial stakeholder feedback and progress to date against the existing strategy:

- Improve the respite offer (including sitting service, residential, crisis, OOH support) for carers of people living with dementia – this work should be undertaken to amplify the dementia specific benefits within the All Age Integrated Carers Strategy
- Investment in new high quality short and long term care dementia facilities to meet growing demand particularly for dementia nursing beds – this work should be scoped within the context of the Care Home Improvement Strategy “The Art of Outstanding”
- To develop new forms of supported housing, extra care and other accommodation models to support community living to avoid inappropriate or premature admission to residential or nursing care – this work should inform the implementation of the work carried out by Imogen Blood and Associates “Housing and Support for Older People In Liverpool” October 2017
- To work with a wide range of partners to further build an effective and vibrant prevention, social prescribing and asset-based well-being offer
- To review the current offer to maintain people with dementia in their home/community setting and identify gaps in provision
- Review the dementia care pathway across the health, housing and social care economy, including the Care Navigator role and intensive psychiatric inpatient services within Merseycare
- Review the current Delayed Transfers of Care (DTC) performance and reporting in relation to dementia specific patients

Appendix 2

How Dementia Action Liverpool did the work

The project team consisted of the three DAL Directors, the co-chair of SURF (Service Users Reference Forum) and the Service Manager from Chinese Well-Being; administrative support was provided by the Life Story Network (LSN). LSN also won the tenders to do the desktop review, which was completed in September (see *Supplementary Document A*), and to assist with the engagement work.

The desk top review compared what local people with dementia and their carers told us with the national standards set out in *The Dementia Care Pathway – Full Implementation Guidance (2018)*⁹. It then mapped progress against the 2014-2018 strategy and highlighted areas for further consideration in the refresh of the strategy.

We devised a template to capture feedback, asking four questions:

- What works well?
- What could be better in existing provision?
- Where re the gaps?
- What are the top three priorities for inclusion in the strategy?

Given the potential reluctance of people from the various BAME groups to talk to us in the light of the funding cuts in 2017 to the BAME Dementia Champions service, we agreed to produce a Position Paper setting out the history and the current position to ensure that we had a good understanding before we embarked on the engagement process; this was shared with our commissioners in June 2018 and is attached as *Supplementary Document B*.

We held a series of introductory meetings with individuals and with existing forums to explain about the work and encourage feedback; we circulated a similar invitation with the feedback template to Dementia Action Alliance members. In July 2018 we ran two open events, inviting anyone with an interest in dementia to come and share their experiences, ideas and concerns. Both included a SURF member living with dementia and a Tide carer as introductory speakers. The events attracted 64 people in total, including people with dementia and carers.

Our 'As is' Position Paper – 'Where are we now?' – was produced in September 2018; this is *Supplementary Document C*.

Five workshops for BAME groups and five person to person interviews were held in September and October, involving 122 people from the Chinese community, Irish

⁹ NHS England Accessed 091218 at <https://www.england.nhs.uk/mental-health/dementia/implementation-guide-and-resource-pack-for-dementia-care/>

and Irish Travellers, South Asian Carers Network and African and Afro-Caribbean communities. The report of the BAME Engagement is attached as Supplementary Document D.

We organised a conference on housing and dementia in October, attended by over 100 people, as a consequence of which a dementia and housing forum is being set up to be led by the sector.

Engaging with GP practices proved to be a protracted process but with the assistance of the CCG and their GP lead for dementia we were able to meet with four practices.

As the work progressed, we met with other interested parties to pursue particular themes and ran additional workshops on specific topics that merited more detailed exploration: short breaks, end of life care, assistive technology and younger people with dementia. We also ran a workshop for professionals and clinicians to get feedback about our emerging findings.

See Appendix 5 for a full list of organisations and individuals who met with us.

We had regular meetings with the city council and CCG commissioners, attended two meetings of the Clinical Operations Network and presented initial findings to the Adult Health and Care Select Committee in November.

We received written submissions from the House of Memories (Liverpool Museums), the Alzheimers Society, the LDAA Transport Group and L'Arche.

Appendix 3

What the 2014-2018 strategy says

The joint CCG and City Council strategy was produced under the overarching vision of the Healthy Ageing Programme: *‘To keep people in Liverpool living at home for longer by positively maximising independence supported by carers, families, communities and services. When people do need care, this will be of high quality, based on personal needs and delivered seamlessly across health and social care’.*

The aim of the strategy is:

‘to establish a plan of action that will ensure that by 2016 , all people with dementia in Liverpool will have equal access to high quality integrated services across health and social care, with excellent post diagnostic support and that Liverpool will be considered by people living with dementia and their carers to have progressed in its ambition to become recognised as a ‘dementia friendly city’.¹⁰

The specific objectives are:

- Continue to work with community groups, stakeholders and people living with dementia and their carers, through the Liverpool Dementia Action Alliance, to raise awareness and understanding of dementia in the city and make progress in our ambition to be recognised as a dementia friendly city
- Ensure that people receive a diagnosis in a timely and appropriate manner, increasing the diagnostic rate from 55% to 70% by March 2016
- Work with people with dementia and carers to continually improve dementia care and work towards Liverpool being recognised as a dementia friendly city
- Develop an integrated network of care provided by health and care professionals across community and specialist secondary care services which offer timely access to diagnosis and provide accessible specialist support when required. This will include developing options to deliver access to crisis support 24/7.
- Commission high quality post diagnostic support tailored to meet the needs of service users
- Increase the numbers of carers who are identified and receiving an annual carers assessment of needs by 20%

¹⁰ This was a five-year strategy so it is unclear why the target date was 2016

- Commission high quality social care to support people living with dementia and their carers and work to reduce social isolation
- Work with local hospital trusts to ensure good hospital care is provided for people with dementia
- Stimulate housing provision that is supportive of people with long term conditions including dementia

Appendix 4

The findings (what people told us)

Awareness and Understanding

2014-2018 Strategy Aim: Continue to work with community groups, stakeholders and people living with dementia and their carers, through the Liverpool Dementia Action Alliance, to raise awareness and understanding of dementia in the city and make progress in our ambition to be recognised as a dementia friendly city.

Progress by 2018: Liverpool DAA has more than doubled its membership to 68 organisations since the current strategy was launched in 2014 and is registered as a community working towards becoming dementia-friendly. It has run local events on transport, design, dementia friendly businesses and housing as well as working through its sub groups – diversity, transport, community engagement and education and SURF (Service Users Reference Forum). The DAA’s business forum meets twice a year and a sector-led housing forum is about to be established in the city. DAA members run frequent Dementia Friends sessions as well as those provided by other Champions in Liverpool. The number of Dementia Friends has grown from 6495 in November 2014 to 20858 currently and there are 70 active Dementia Friends Champions available to run sessions.

Feedback during the strategy refresh suggested that awareness of dementia has improved generally in the city, related in part to DAA activity and member initiatives – but there is still a long way to go.

On 6 February 2018 the Liverpool City Region (LCR) Health and Well-being Summit launched its Dementia Pledge, signed by local authority representatives and with the aim of helping the region to become dementia-friendly. It comprises ten commitments that include ‘Form and be enthusiastic members of Dementia Action Alliances’ and ‘Promote dementia awareness and understanding’. An LCR working group is tasked with making sure that these commitments are translated into action across the region.

Despite this progress, people with dementia and their carers told us of examples of insensitivity, intolerance and poor physical environments in shops and other businesses and on transport. There is also a shocking lack of awareness and understanding about dementia in some health, residential and home care services.

Participants in the workshops for the various BAME communities confirmed that the withdrawal of funding for the Dementia Champions has meant that the awareness raising previously undertaken is now on a smaller scale and in some communities has ceased altogether. Indeed, several people told us that provision for people with dementia from BAME communities had got worse, not better, over the last four years. Further, no-one in the BAME Community Development Team commissioned by the CCG is working with people with dementia. The importance of culturally appropriate information and support was emphasised –

“If it wasn’t for Tea House, we would not be able to recognise the early signs and symptoms of dementia.”

“The Dementia Champion has provided us with a lot of information about dementia and about the provision of dementia services in Liverpool. We also get advice on how to live well with dementia.”

The African and African-Caribbean participants commented that

“there is now a more open discussion about Dementia and its effects on patients and families”.

However, others suggested that:

“Many people don’t want to identify as having Dementia so sometimes not labelling an event as such may help get more people at events and getting access to information”.

Our session with members of Merseyside Society for Deaf People (MSDP) highlighted similar difficulties. Awareness and understanding of dementia amongst the deaf community is limited. The community is dispersed and individuals easily isolated; this is exacerbated by the low level of signing in the health and social care workforce. Although the Society itself is a lifeline and its centre used by over 300 people, it is not known how many of these have a diagnosis of dementia.

Seeking help

2014-2018 Strategy Aim: there is no specific aim relating to help-seeking although the strategy does refer to timely identification and diagnosis within targeted high-risk groups.

Progress by 2018: Seeking help depends on recognising that you may have memory or cognition problems; knowing where to go to ask for help and advice; and being confident that your concerns will be taken seriously and that you will receive a sympathetic hearing. Often the emphasis in the media and in public health messages is on memory loss and dementia is portrayed as a problem of old age, which may put some people off from seeking help; early symptoms of Lewy Bodies dementia, for example, do not usually include difficulties with memory, yet it is the most common form of dementia after Alzheimers Disease and vascular dementia. Often it is family or friends who notice differences and persuade the person to go to the GP; unfortunately, we still heard stories of carers being excluded from discussions by some GPs under the guise of patient confidentiality. Others told us that their GPs were excellent, exploring other diagnoses before referring their relatives to the memory services.

People from BAME communities may face particular challenges:

“I don’t think there is much support for BME communities dealing with dementia. I care for my mother-in-law and my husband didn’t think it was right to even talk about my mother in law’s symptoms with the GP but she was causing some dangerous situations at home and following this my husband let me speak to the worker at Mary Seacole House who then supported us to go to the GP”

The majority of the Irish and Irish Traveller group felt that ‘GPs and medical staff had no experience or knowledge in treating dementia... GPs did not know how or what to advise patient/carer’.

The following contribution from the South Asian Carers Network sums up some of the difficulties:

“There is huge focus on the shame attached to disclosing that a family member has dementia. This is due to the community perception of

dementia and mental health overall. One of the participants stated that even accessing counselling services for generic reasons can bring shame and people think the person is mad. This is what stops people from accessing services and asking for help. It is hard to tackle the issue of shame from the community. People struggle to trust people as they are scared that their communities will find out their issues.”

Getting a diagnosis

2014-2018 Strategy Aim: Ensure that people receive a diagnosis in a timely and appropriate manner, increasing the diagnostic rate from 55% to 70% by March 2016

Progress by 2018: Once referred to Merseycare by the GP, people are assessed at home by a doctor within six weeks (currently four weeks in practice), which may involve further tests or scans, including neuropsychological tests if the diagnosis is unclear. A diagnosis of dementia is not given until the clinician is sure this is right. Although the length of time to get a diagnosis varied considerably (more than two years for some), most people described the professionals and clinicians they came across along the way as ‘good’ and helpful. The gap was in knowing what was happening and why more tests were undertaken or further clinic appointments awaited; this was a particular concern for younger people whose diagnosis might be more complicated. GPs who met with us confirmed that the process has improved and that in their view getting a diagnosis is quicker for most people than previously.

The process was not straightforward for some of the workshop participants from BAME communities:

“The GPs and nurses should have been more proactive in getting me diagnosed when I had concerns about dementia and also to get involved with my family sooner. This would have got me on the right track for me to be able to deal with my dementia”

“Lack of diagnosis and support from practitioners resulting in misdiagnosis”

Assessments and explanations rely on verbal expression and vocabulary rather than visual expression. For example, a deaf person could probably describe the current

Prime Minister but may not know her name. British Sign Language (BSL) interpretation can also be perceived as a barrier. Deaf people may therefore have difficulty explaining what is happening to them or someone they are looking after to professionals, so they are often referred late by GPs for assessment. The National Neurological Hospital runs a monthly clinic in London with trained professionals using BSL, so there is no need for an interpreter.

At diagnosis, the clinician should

- Give out the leaflet drafted and agreed with SURF (this contains some basic information about dementia and services and what to do next) along with a more substantial information pack about the services and support available
- Offer the post diagnostic support programme
- Confirm referral to the care navigator and explain their role
- Consider whether CMHT involvement is required for people with more complex needs

It is extremely disappointing that the diagnostic rate has been falling steadily since its high point of 78% in 2015; despite a slight upturn in 2016 following a concerted effort by the CCG to target specific GP practices, the rate in November 2018 had fallen to 69.7%, below the modest target in the One Liverpool strategy. The variable rates of diagnosis across GP practices suggest that leadership and concerted action are required again.

Post diagnostic support

2014-2018 Strategy Aim: Commission high quality post diagnostic support tailored to meet the needs of service users.

Progress by 2018: The Clinical Dementia Network envisaged by the current strategy is now working well. This means that anyone receiving a diagnosis of dementia in the Walton Centre or at the Royal Liverpool Hospital should be referred direct to Merseycare for their post-diagnostic support programme, without having to return through the GP. Further, it is now possible for everyone to receive the same information about dementia. Currently about 60% of people referred take up the offer of post diagnostic support; the 40% who choose not to attend the post diagnostic support groups are supported by a dementia care navigator.

We heard some comments from people with dementia and carers that the service in North Liverpool is still not as good as that provided at Mossley Hill. However, we were advised by Merseycare that the offer across the city is now the same and that

these comments may refer to people's experiences previously. People have a choice of location (in both north and south Liverpool), day of the week and time of day. There are usually six groups running at any one time. Merseycare runs Saturday courses several times a year that are open to anyone who has not taken up the offer of the eight-week course or those who would benefit from a 'top-up'.

Merseycare offers interpreters for different languages, including BSL, however language barriers are still believed to exclude many from accessing mainstream services at the Carers Centre and Mossley Hill Hospital, including the post diagnostic support programme. Participants in the Chinese Network event believe that "the lack of language support creates an inequality in the care system for people from BAME communities." It would be possible for Chinese Well-being to translate course materials and run their own post-diagnostic support programme, as several staff underwent training as part of the BAME Dementia Champions initiative.

As a result of the clinical network it is possible for everyone to receive the same information about dementia. An information leaflet co-produced with people living with dementia and carers is now available to be given out when the person receives a diagnosis by the doctor. This contains some basic information about dementia and services and what to do next. Once the person has received their diagnosis, they also receive a more substantial information pack about the services and support available. If a person chooses not to attend the post diagnostic support groups then they are supported by a dementia care navigator.

"The system should be that if you're diagnosed with dementia you should be put in touch with a Care Navigator, but there are not enough of them"

The care navigators are in place; their role has been evaluated and the benefits recognised but only four out of the recommended twelve posts are funded. They are therefore overstretched and cannot be as pro-active as the original role envisaged. Everyone with a diagnosis should be on either their active caseload, with regular contact negotiated individually, or their inactive caseload, if the individual is under the care of the Community Mental Health Team, when they would receive a six-monthly contact. Dementia care navigators have access to the clinical network should needs change.

Living as well as you can

2014-2018 Strategy Aim: Work with people with dementia and carers to continually improve dementia care and work towards Liverpool being recognised as a dementia friendly city Increase the numbers of carers who are identified and receiving an annual carers assessment of needs by 20%

Commission high quality social care to support people living with dementia and their carers and work to reduce social isolation

Stimulate housing provision that is supportive of people with long term conditions including dementia.

Progress by 2018: The SURF group is well established and growing, co-chaired by a person with dementia and a former carer. It drives the priorities of the DAA and its members are involved in all the DAA sub groups. SURF members join the last session of Merseycare’s post-diagnostic support programme to tell newly diagnosed people about its activities and invite them to join. Their contribution to various events has been consistently powerful.

SURF clearly plays a significant role in the lives of its members and we heard many positive comments about its role:

“I meet other people, I have opportunities to put a little back in and support other people”

“SURF creates connections and friendships”

“Informal peer support as offered by SURF is crucial”

SURF and other peer groups, such as those run by Everton in the Community, are crucial in enabling people to live active and connected lives. They provide safe spaces where individuals are understood and accepted and are often the source of information and ‘top tips’ about managing life with dementia. In crises, carer members may call each other for support and advice. When the Alzheimers Society closed its services in Liverpool in 2017 after the withdrawal of CCG funding, SURF members stepped in to continue running one of the memory cafes and a singing group.

However, despite the pledge in the 2014-2018 strategy, people with dementia, carers and the LDAA were not consulted about the funding reductions and their impact. Attendance by the LCCG and LCC at the LDAA and at SURF tailed off in 2016-17 after changes in personnel in both organisations, so opportunities to share information and get feedback were not taken. These gaps were rectified by both organisations during 2018, resulting in more honest conversations and improved exchanges of information. People told us during this engagement process of the importance of having their voices heard and for such an approach to be embedded in the structures and practices of the LCCG and LCC.

For some groups, access to services after diagnosis is problematic – do you attend a memory café with your own BSL interpreter, for example? BAME groups highlighted the need for specific culturally appropriate day services, with language support for individuals with appropriate activities.

“My granddad would love to be go out but there is nowhere for me to take him where people speak his language (Arabic).”

Liverpool is fortunate in having a rich array of services in the city, many run by community and voluntary sector organisations, but lack of knowledge and awareness about what is available and how to access them was a recurring theme. The ‘Live Well’ directory of services commissioned by the city council and provided by Healthwatch offers a wealth of information, but it is not themed under ‘dementia’ and is an on-line resource. People told us that, despite regular promotion by Healthwatch on the local radio and other means, many are unaware of its existence or that telephone help is available for those unable to use the internet.

“There’s an assumption you know how the system works and what to do”

“We want to know what is out there.”

“My knowledge in relation to what is available is very limited. We get most of our support from Mary Seacole House and if we need anything additional or specific we will be signposted through Mary Seacole House and supported to access the alternative support”.

People who are on their own face particular challenges:

“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”

However, carers reported a mixed picture. Whilst 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?”

- others appeared to be unaware that their patients were carers and made no allowances. Some staff do not even recognise carers and their role

“If you have a good one – it’s great, but if you don’t – it’s a disaster!”

Few carers are identified on GP registers and even if they are, they may not be cross referenced with the person with dementia if they are in the same practice. One GP practice told us of the importance of working closely with home care agencies in their patch – which they described as excellent – as they are often the eyes and ears for picking up changes in behaviour or deterioration in health.

Carers emphasised the importance of looking after their own health and professionals being alert to this:

“Well Carer’ clinics – like Well Woman clinics. Could include a physical health check as well as mental health.”

Direct Payments are a potential means of enabling individual support with greater control for the individual. Some people reported that they had proved very beneficial, but the facility is not well known and people told us that is poorly promoted by social services: “they keep it under their hat!” Liverpool has a low take up of Direct Payments for people with dementia – at 2.5%, the percentage is the same as in 2014.

Assistive technology can provide additional help for people, especially in the early stages of dementia, along with reassurance for carers. Several people with dementia told us they use ‘tracker’ and way-finding devices to help them get around and prevent them getting lost; apps on smart phones were also valuable tools. MerseyCare staff told us that going out and getting lost, particularly at inappropriate times such as during the night, is often the tipping point for people at risk of needing residential care and that tracker devices may help prolong the time that people can remain living at home. Issues concerning informed consent can cause some difficulties for commissioners.

Several professionals in the city had heard of the Meeting Centres programme. This is a Dutch model that offers day time opportunities in community facilities for people

with dementia and carers, who are actively involved in running the Centres¹¹. Following the successful establishment of two Centres in the West Midlands, the University of Worcester has been funded to support the development of further Centres across England. There is potential in Liverpool and the DAA has agreed to convene a meeting of interested parties in early 2019.

The current narrative, arising from the 2009 English National Dementia Strategy, is to help people to ‘live well’ with their dementia. This was at the request of people with dementia involved in the development of this strategy, to mitigate the stigma and negative stereotyping of dementia. However, increasingly this approach is being questioned, as some people, especially in the advanced stages of dementia, struggle to live well and the term risks making carers feel guilty. We therefore suggest the aim should be to help people ‘to live as well as you can with dementia’.

Changing needs

2014-2018 Strategy Aim: Develop an integrated network of care provided by health and care professionals across community and specialist secondary care services which offer timely access to diagnosis and provide accessible specialist support when required. This will include developing options to deliver access to crisis support 24/7.

Work with local hospital trusts to ensure good hospital care is provided for people with dementia.

Progress by 2018: Despite the successful establishment of the Clinical Network in relation to diagnosis and post-diagnostic support, there has been no progress in developing crisis support. CPNs are available up to 9 pm during the week and for a few hours at the weekend. Outside those hours, people have to rely on locum GP services, 999 and the emergency social services care-line. This was one of the most pressing needs that emerged from the engagement events, not only for people with dementia and carers but for service providers too, who told us that they struggle to get advice out of hours if a care home resident is distressed, agitated or unwell. Often, they have to resort to either sedation or using 999, both of which result in poor outcomes for individuals. Liverpool’s high rate of emergency hospital admissions probably reflects this. GPs told us that effective crisis support was one of their top priorities for the new strategy.

¹¹ Further information available at <https://www.worc.ac.uk/discover/34388.html>

“Out of hours, after 9 p.m. the system stops. I have to call 999 and go into A&E, and I don’t want to do this. Is there a time when the NHS stops?”

Carers told us that often what they need most of all is someone to talk to who knows about dementia and who can advise and reassure. They do not want to talk to an answering service or a call centre and although there are national helplines available, they want to talk to someone who has local knowledge. In these circumstances they will ring another carer as someone who knows and understands their circumstances:

“We need a crisis line but with somebody on the other end, not a recording, who can come out if necessary.”

Liverpool has recently benefitted from Department of Health funding to extend social prescribing which is currently not well known amongst people with dementia and carers. Advice is available on prescription from the Citizens Advice Bureau (CAB). The GP refers by phone to the CAB, whose support worker rings the individual and asks ‘How can we help?’ Although this is primarily finance and debt related so far, the aspiration of LCCG is to remove barriers to accessing community assets and to help professionals identify non-clinical needs. Already GPs in South Liverpool have picked up that social isolation is as significant a problem as debt. There is potential here to enrich the lives of people with dementia and carers, perhaps in conjunction with a re-vamped carers voucher scheme, as described in the next section on ‘Getting a break’.

Much progress has been made in both the Royal Liverpool and Aintree hospitals in dementia training for their staff, identifying patients with dementia and in improving the physical environment. People told us examples of sensitive, compassionate care where carers were welcomed and involved. However, we also heard accounts of staff not knowing how to calm people’s agitation, assist people to eat or drink or involve families in planning discharge home:

“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.”

There were similar concerns about some home care and residential care services; recruitment and retention of staff are clearly significant problems, especially as home care providers told us that many staff benefit from basic training, gain experience, then move on to work in the NHS where there are better pay and conditions and a potential career structure. The system is under pressure and staff may be rushed to carry out all the visits required:

“There needs to be more time for carer/nurse. They can be in and out and I am not sure what goes on or what they have done. It’s not their fault. It’s the restraints [constraints] on them.”

Liverpool city council is investing in three hubs which will include residential and specialist nursing care for people with dementia; the first is due to open in Speke in the summer of 2019. This development is welcomed but there are concerns that none of the three homes will be in areas of the city with significant multi-ethnic populations, given that currently there is little residential provision for people who have additional cultural and language needs. People can be totally isolated in a home if no-one speaks their language or understands their dietary needs and preferences. The nearest care home for deaf people who use BSL is in Blackpool.

There are concerns that the three new hubs will have a negative impact on recruitment and retention for other care providers. It is essential that care providers are included in the development of the joint workforce strategy currently in production.

Given that they will be a 24-hour service, the hubs present an opportunity to explore how an out of hours crisis service could be developed, building on existing evening CPN availability.

It was disappointing to hear from people with dementia and carers that some professionals and provider organisations are still not communicating and sharing information with each other. The single point of access is still not a reality and people may have to repeat their story several times in seeking help. One elderly carer had waited all afternoon for a telephone call back to her enquiry that morning about provision of aids for the shower – only to be told that she had rung the wrong department and would have to start again.

Understanding and coping with people’s distressed behaviour is one of the biggest challenges for carers. Although the CMHT provides valuable advice and support, they may not have the time to devote to individuals. Several people suggested that an Admiral Nursing service would meet this need and that such an investment could reduce crisis admissions to hospitals.

“Admiral Nurses – specialist dementia nurses as there aren’t any at the moment e.g. like cancer nurses.”

Getting a break

2014-2018 Strategy Aim: Commission high quality social care to support people living with dementia and their carers and work to reduce social isolation.

Progress by 2018: Alongside out of hours support, respite care or short breaks emerged as a pressing need. We decided to talk about ‘short breaks’ rather than ‘respite care’ as it matters to people with dementia and their carers that the break is a positive experience for both parties and is not just about carers receiving respite from a burden of caring. Currently the offer is limited to two weeks in a care home and using carers vouchers to secure a sitting service while the carer goes out. Neither options are meeting people’s needs. Although residential respite works for some people, most told us that it was almost impossible to book a place more than a few days in advance. There are no designated respite beds and the onus on the carer is to find a vacancy; this can involve ringing round every home in the city with no guarantee of success. This makes it extremely difficult for carers to book a holiday or other break in advance. Residential care may also not be the best way of providing a positive experience for the person with dementia, who may find the unfamiliar environment disorientating and distressing, especially if they cannot book in to the same home each time.

The carers’ voucher scheme poses similar difficulties in terms of availability and reliability. A recent review by Healthwatch¹² confirmed the views gathered during this engagement process. Paid staff are often not available when needed, especially if the request is ad hoc and not a regular request on the same day of the week. The paid carers are provided by home care agencies, but the staff are not allowed to provide personal care, prompt for medication or take the person out – the very tasks that they would normally carry out for people as home carers and which the carer needs to know are being undertaken while they are out of the house. The reason given for this by commissioners is that the service is for carers and if such care was provided for the person with dementia, it would have to be charged for. This is so remote from people’s needs that it must be addressed; the purpose of the scheme is

¹² Carers Voucher Scheme Report, September 2018 Healthwatch Liverpool accessed 08.12.18 at <https://www.healthwatchliverpool.co.uk/report/2018-10-10/carers-voucher-scheme-report-september-2018>

to enable carers to take a break, so it is essential that the person with dementia is looked after appropriately in their absence.

Several carers knew nothing about the voucher scheme, even when they were receiving a social care package. Others need a break too:

“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”

Further, the crisis may arise because the carer is ill, rather than the person with dementia, who will then require substitute care. Getting a rapid response can prove difficult.

People want more choice beyond two weeks in a care home: “One thing doesn’t suit everybody”. There are several opportunities to develop a wider range of options for short breaks for example:

- My Time, organised by Local Solutions, utilises spare capacity in the leisure and hospitality sector to give carers a break. Carers told us it works well and they value it highly.
- Shared Lives (sometimes called adult placement) is a scheme where adults needing care or support share the home of trained carers. Although it operates in the city it is not well developed for people with dementia.

End of life care and post-bereavement support

2014-2018 Strategy Aim: there is no specific aim relating to end of life, palliative or post-bereavement care and they did not feature in the priorities already identified

Progress by 2018: This topic emerged during the open community events and we decided to run a specific workshop to consider the issues. This confirmed that people with dementia and carers value the opportunity to talk about end of life care and that it is often the professionals involved who frame this as ‘difficult’. Good communication from professionals was emphasised: listening to family concerns, delivering news in a sensitive way; inviting the family to meetings; and (most importantly) making time.

GPs play an important role here. We heard of an example of a GP spending two hours in total discussing the options available, involving the family as well as the person with dementia. People described a limited understanding among

professionals of the double loop bereavement experienced by many carers: dementia changes family dynamics; although the person is still there, they may seem to be 'lost' to the carer; and there are often high levels of frustration and distress for both. Professionals were often unaware of available options such as hospice care so were ill-placed to offer advice. Overall, there was a plea for honesty from professionals when discussing end of life care.

Post bereavement care varied considerably. Some GPs followed up with a home visit or a phone call whilst others were silent. Carers found it particularly distressing that not only did they have to cope with the bereavement, but they often had to do this alone as all the support had been geared towards the person with dementia:

“everything stops when the person dies.

Commissioning and service design

2014-2018 Strategy Aim: To work collaboratively with people with dementia and carers to improve dementia services; to commission high quality post diagnostic support; to commission high quality social care to support people living with dementia and their carers and work to reduce social isolation.

Progress by 2018: Our work with people with dementia and carers puts us in awe of their generosity in wanting to use their own experiences – good, indifferent or poor – to influence future service provision. As noted previously, such two-way feedback must be embedded in the way that the LCCG and LCC go about their business of commissioning for their local population. Some concerns were raised by both the voluntary and independent sectors that they are not regarded as equal partners who can offer solutions and are not as involved in planning and service design as they believe they should be; they were not part of the process for developing the 'One Liverpool' strategy¹³, for example. One care home provider told us that she believed she could offer two beds for short breaks on an on-going basis and was confident that they would be well-used, but would need some assurances from the LCC about funding. There are clearly some gaps in provision for particular needs – short breaks, cultural and language needs, out of hours support for example – and we were encouraged by the view of one LCC commissioner that they should 'go to the market' to discuss what was possible. In doing so, it is important that commissioners have regard to the ethics of decision-making and commissioning

¹³ One Liverpool: 2018 – 2021 Liverpool CCG, 2018 accessed 08.12.18 at <https://www.liverpoolccg.nhs.uk/media/3066/one-liverpool-plan-2.pdf>

strategies. Bob Hudson (2018)¹⁴ suggests that these are ethical employment, tax compliance, transparency, localism and ethical vision.

The commissioning of the three residential hubs offers an opportunity to have a wider discussion with providers about how they might meet unmet needs that makes the best use of expertise and experience, ensures improved supply, avoids perverse impacts on workforce recruitment and retention and delivers value for money, as endorsed by the Public Services (Social Value) Act, 2012.

¹⁴ Hudson, Bob The only way is ethics: a new approach to outsourcing social care The Guardian, 20.08.18 accessed 08.12.18 at <https://www.theguardian.com/society/2018/aug/20/ethics-new-approach-outsourcing-social-care>

Appendix 5

Meetings with organisations and individuals

- Aintree Park GP Practice
- Steve Green, Brenda Stagg, Rachel Yates, Alzheimers Society
- Breeze Hill Health Centr
- Dil Daley, Chief Executive, Age Concern Liverpool and Sefton
- Bradbury Fields consultative group
- Suzanne Love, The Brain Charity
- Care Home Providers Forum
- Happy Older People Network
- Marie Hanson, Henshaw's
- Sarah Thwaite, Healthwatch
- Home Care Providers Forum
- Dawn Carroll, House of Memories
- Learning disabilities provider forum
- Liverpool City Region Older People's Forum
- Samantha Clements, commissioner (end of life care), Liverpool CCG
- Carole Hill, Director, and Tom Fairclough, commissioner (mental health), Liverpool CCG
- Clare Mahoney, commissioner (social prescribing), Liverpool CCG
- Fiona Ogden-Fforde, lead GP for alcohol and healthy ageing, Liverpool CCG
- Martin Farran, Director of Adult Services and Health, Liverpool city council
- Natalie Markham and Andrew Durkin, Liverpool city council
- Ann Williams, commissioner (assistive technology), Liverpool city council
- Merseycare Community Mental Health Team
- Merseycare Memory Service
- Merseyside Centre for Deaf People
- Merseyside Pensioners Association
- Merseyside Police Community Forum (via e-mail circulation)
- Moss Way GP Practice
- Picton neighbourhood meeting
- Older People's Housing Forum
- Sean Lever, Dementia Lead, Royal Liverpool and Broad Green University Hospital Trust
- Dr Neil Carmichael, Consultant Geriatrician, RLBGUH (by e-mail)
- Residential hubs Project Board
- Helen Black, Shaw Healthcare
- Dr Rhys Davies, Walton Centre
- Welfare and Well-being Organisations Network

Events

3 July	Community event – South Liverpool
5 July	Community event – North Liverpool
9 July	Community Event – Chinese Wellbeing Dementia Support Network plus Community Elders
25 July	Community event – Chinese Wellbeing/Hoi Yin Association
2 October Network	Community event – Mary Seacole House – South Asian Carers
2 October	Workshop – end of life care
9 October Travellers	Community event – Irish Community Care – Irish and Irish
12 October	Housing and dementia conference
15 October	Workshop – short breaks
24 October Caribbean	Community event – Back to Life Liverpool – African and African-
26 October	Workshop – younger people with dementia
30 October	Presentation to Health and Care Select Committee
31 October	Workshop – assistive technology
1 November	Consultation session – Merseyside Society for Deaf People
5 November	Workshop for professionals and clinicians

Draft Preliminary Implementation Plan

Strategic Objectives	Action Required
Continue to raise awareness and understanding of dementia, including all communities, providing information in appropriate languages and formats and working with Liverpool DAA to reach beyond the health and care sector	<ol style="list-style-type: none"> 1. Continue awareness activities, including Dementia Friends sessions, across all sectors 2. Develop bespoke training for specific sectors e.g. housing, transport 3. Ensure needs of BAME communities, younger people and people with sensory impairments are included and that accessible materials are produced in appropriate formats
Increase timely and appropriate diagnosis year on year, aiming for 80% by 2024	<ol style="list-style-type: none"> 1. Target GP practices where diagnostic rate is low 2. Work with public health to promote messages to the public about prevention through healthy lifestyles and the benefits of timely diagnosis
Ethical commissioning of high quality post-diagnostic support that meets the need of particular groups and communities, includes equitable access to dementia care navigators and increases the take-up of the initial offer of post-diagnostic support from 60% to 80% year on year to 2024	<ol style="list-style-type: none"> 1. Ensure recurrent funding for Merseycare's post diagnostic support programme 2. Review referral processes to increase take up of post diagnostic support to 80% by 2024 3. Work with BAME communities to develop bespoke post-diagnostic support where appropriate <p>Increase dementia care navigator capacity – aim for three additional posts in first year</p>
Develop options to deliver access to crisis support over 24 hours	<ol style="list-style-type: none"> 1. Develop effective and accessible out of hours services that ensure an effective response for people with dementia and carers living at home and for service providers 2. Consider commissioning an Admiral Nursing service to support carers of people with complex needs, to reduce crises occurring
Develop options to deliver short breaks that offer choice and provide positive experiences for people with dementia and their carers	<ol style="list-style-type: none"> 1. Revise the carers voucher scheme to ensure that it meets the needs of carers to take a break and people with dementia to receive a substitute service 2. Work with willing providers to develop designated 'short break' residential beds that can be booked in advance

	<p>Explore opportunities with the community and voluntary sector to offer a choice of short breaks other than in residential care</p>
<p>Ensure that people with dementia and carers are involved in planning and service re-design</p>	<ol style="list-style-type: none"> 1. Review current arrangements for involvement and feedback <p>Ensure attendance by LCC and LCCG at SURF and LDAA meetings</p>
<p>Use the opportunities created by the commissioning of the three residential hubs to work with the community, voluntary and independent sectors to make the best use of experience and expertise to develop solutions to meet gaps in current provision</p>	<ol style="list-style-type: none"> 1. Work with willing providers to identify opportunities to meet specific needs <p>Involve all sectors in the development and implementation of a workforce strategy across health and social care that recognises the interdependence of both and the role that social care plays in providing basic entry level experience and induction training and which benefits the NHS</p>
<p>Make the best use of community assets, ensuring that social prescribing includes people with dementia and carers, and explore the potential for developing 'Meeting Centres' in Liverpool</p>	<ol style="list-style-type: none"> 1. Review current arrangements for social prescribing 2. Raise awareness of GPs of the potential of social prescribing to benefit people with dementia and carers <p>Bring interested parties together to consider how 'Meeting Centres' might be developed in Liverpool</p>

--ENDS--