

Refresh of Liverpool's Joint Dementia Strategy

Where are we now?

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Introduction

This aim of this paper is to provide an overview of the current position in relation to living well with dementia in Liverpool. It is based on:

- Data supplied by Liverpool City Council and Public Health England
- Desk top analysis of policy, best practice and progress on the existing local dementia strategy, undertaken by the Life Story Network on behalf of Dementia Action Liverpool
- Internal reports provided by Liverpool City Council and CCG
- Information and feedback gathered through meetings with individuals and organisations

Data

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 registers¹. The number of people diagnosed with dementia is expected to rise to 5663 in 2021². The diagnostic rate is currently 70%, above the national target of 66.7% but less than the 76.5% achieved in 2015 and 78% in the previous year. The 'One Liverpool' plan³ 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 are 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 did not record the information.

Other Liverpool data^{4,5,6} relevant to the local strategy are:

- 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

¹ 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

² Progress on Liverpool dementia strategy (2016), Liverpool CCG

³ One Liverpool: 2018-21 *The Long and Winding Road to a Healthier Life* (2018) Liverpool CCG

⁴ Public Health Profiles: Dementia profile for Liverpool, as above

⁵ Adult Social Care Workforce return 2016-17, Liverpool City Council

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

- 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.

What have people told us?

During the last six months we have met with numerous organisations and individuals, including commissioners, social care provider forums and voluntary sector organisations. We have dates to meet with three GP practices and are awaiting confirmation of a further two. We have run two open community events and two workshops for the Chinese community; further workshops for other BAME groups will take place in October. We have met with Merseyside Centre for Deaf People, Henshaw's and Bradbury Fields to discuss the particular needs of people with sensory impairments and will be meeting with their user groups in the next few weeks. SURF (Service Users Reference Forum) and Tide (Together in dementia everyday) have worked with us to ensure that people with dementia and carers are fully involved and that their voices are heard alongside those of the experts.

The Desktop review report sets out in detail what people have told us matters in relation to living with dementia in the city, so we can summarise feedback from all these sources as follows:

1. Access to diagnostic assessment and post diagnostic support is still patchy and although there have been improvements in the last few years, much can still depend on which part of the city you live in. Those who do access these services report a high level of satisfaction; Mossley Hill's post-diagnostic support programme is highly valued, along with the dementia care navigators – but there are not enough of them for the city and they are overstretched.
2. Access to information and advice, at the right time and in digestible formats, remains problematic. Some people can feel overwhelmed by information provided on diagnosis and set it to one side, then have difficulty retrieving it or accessing information anew. People living on their own, who have no family support or whose families live a distance away, find it particularly difficult to

access information and advice. Healthwatch is commissioned to provide the LiveWell directory and has Information Officers available on the telephone for those who do not use the internet.

3. Despite recent funding cuts to the voluntary sector and consequent reductions in services, there is a wide range of activities and opportunities available in the city – but many people do not know about them. People with dementia and their carers stressed the importance of staying active, well and connected to their families, friends and communities. Peer support is crucial in supporting people's well-being and an important source of information about 'what is going on' and what is available – word of mouth remains a significant means of communication, especially for people who do not use computers.
4. People reported that they perceived there has been an increase in awareness of dementia in the city; although this may be due to national awareness campaigns, they attributed the improvement in part to the growth of the Liverpool Dementia Action Alliance and the work it is doing across all sectors to help Liverpool become a more dementia-friendly city.
5. People's experiences of services provided by GPs and primary care are variable. We heard that some are excellent, making sure that carers are 'flagged' on the system and offering fast track appointments in the knowledge that if the carer goes down the person with dementia will need additional support. Others were perceived as indifferent or ignorant in relation to the needs of people with dementia and those of their carers.
6. We heard that out of hours support is difficult to access for care providers as well as people with dementia and carers living at home; after 9 pm and at weekends, there is often little alternative but to dial 999, resulting in what could be avoidable admissions to hospital. The data on emergency admissions support this interpretation.
7. Respite care is unreliable and often unavailable. The standard offer seems to be two weeks in a care home, but this cannot easily be booked in advance and some care homes charge from the date of booking which can be very expensive. The carers vouchers scheme is inflexible and, again, unreliable. Even though the paid carers are provided by home care agencies, they are not allowed to carry out personal care or to take the person with dementia out. The scheme is currently under review.
8. There is a lack of culturally appropriate services in the city. People with specific language, religious or dietary needs find it almost impossible to find a suitable care home and, if they do become resident, may be isolated and receive inappropriate care. It is noteworthy that Chinese Well-being has received an 'outstanding' CQC rating for its home care service. The withdrawal of funding from the voluntary sector for the Dementia Champions service has had a detrimental impact on the numbers of people from BAME groups accessing diagnostic and post diagnostic support services. Merseycare's Community Development service is currently working with no-one from BAME communities.

9. People shared their frustrations that some provider organisations and individual professionals still do not share information amongst themselves, resulting in people having to tell their story many times and misunderstandings about what is needed.
10. Younger people may face delays or difficulties in getting a diagnosis and find that services are geared towards older people.
11. Workforce development was a recurring theme; people want to be supported by staff who are knowledgeable, competent and confident in dementia care. Recruitment and retention are ongoing difficulties; often staff are recruited and trained by home care agencies, then recruited by the NHS where there is a career structure and improved pay and conditions.
12. Finally, people had concerns about end of life care and post bereavement support. People wanted the opportunity to talk about what they wanted for themselves and to make plans for end of life. Carers reported that once the person with dementia dies, all the support stops, leaving them to manage on their own.

What does this tell us?

Liverpool has made good progress in some elements of the existing strategy – the establishment of the Dementia Clinical Network is a significant step forward and there has been investment in the development of the dementia care navigator service. Liverpool city council has commissioned Shaw Healthcare to provide three residential hubs, which will include specific residential and nursing care provision for people with dementia. However, some gaps remain and, in some areas, provision has deteriorated – the diagnostic rate has decreased and funding to the voluntary sector has been cut, resulting in the closure of services run by the Alzheimers Society in the city and the demise of the BAME Dementia Champions. Service responses across the city remain variable. There is still no reliable out of hours rapid response or support service.

This review confirms that we need to focus our next phase of work on the following key priorities:

- Respite
- Out of hours support
- End of Life Care
- Younger People
- Assistive technology

Dates have been arranged to bring together commissioners, providers, professionals, people with dementia and carers to co-design new models of provision. We will also hold a workshop for clinicians and professionals to share our

findings and seek their feedback on proposed developments.

We will work with Shaw Healthcare to help them establish an early presence in the city and to engage with older people, people with dementia and carers.