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April 2018

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### 1 Background

#### 1.1 The dementia review

NHS Sheffield Clinical Commissioning Group (CCG) and partners are undertaking a review of current dementia services and care in Sheffield. The aim of the review is to understand if the needs and expectations of people with dementia and their family and carers are being met, and to look at how the pathway could be improved.

The CCG wishes to identify new models of care that could potentially improve services in Sheffield and make sure that services can meet the growing demand for care and support. Better care has the potential to reduce hospital admissions, improve support for carers, prevent crises, and provide better post-diagnosis advice, information and support.

#### 1.2 What we already know

To give the review the best chance of success, it is essential that the views and experiences of service users, families and carers are heard. The CCG want to involve people with lived experience in planning how dementia care could best be provided.

One of the first steps in this process is to review the existing patient and carer feedback relating to dementia care, to highlight common themes and any gaps that can be pursed in further engagement.

Healthwatch Sheffield has agreed to carry out this review of existing feedback by producing this report that can be shared with all partners.

Following this report Sheffield CCG, along with partner organisations, will be carrying out engagement activities to obtain further views and experience of dementia care - from diagnosis to end of life.

### 2 Methodology

A review of relevant engagement data was carried out by Healthwatch Sheffield between 16<sup>th</sup> and 27<sup>th</sup> April 2018 in response to a brief provided by NHS Sheffield CCG.

Healthwatch Sheffield contacted Sheffield Carers Centre, Age UK Sheffield, Sheffield Dementia Involvement Group (SHINDIG) and Sheffield Alzheimer's Society to request the findings from any relevant engagement work they were aware of.

We also used evidence from Healthwatch Sheffield's Feedback Centre, Care Opinion, publically available complaints information, relevant Healthwatch Sheffield engagement activities and we were sent evidence by Sheffield CCG.

Overall, ten pieces of evidence relating to patient, family and carer views and experiences were included in the review. All the engagement activities were carried out in Sheffield, were relevant to dementia care and were carried out within the last two years (March 2016 – March 2018).

The evidence was analysed for common themes and these themes are summarised in the findings section of the report.

#### Evidence considered in the preparation of this report:

- 1) Carers Strategy Launch Presentation Sheffield City Council: 11<sup>th</sup> January 2017
- 2) Healthwatch Sheffield Feedback centre: March 2016 to March 2018
- 3) Care Opinion: March 2016 to March 2018
- 4) Friends and Family Test (FFT) for Memory Clinic Sheffield Health and Social Care NHS Foundation Trust (SHSC): April 2017 to March 2018
- 5) Consultation on the Proposed Changes To Dementia Services At Hurlfield View And Stocksbridge – Sheffield City Council and Sheffield Health and Social Care NHS Foundation Trust (SHSC): 15<sup>th</sup> November 2016
- 6) Experiences of Home Care Healthwatch Sheffield: March 2018 (awaiting publication)
- 7) Involvement and Engagement of People with Dementia Roadshow SHSC User Engagement Group (SUSEG): October 2017
- 8) SHINDIG 15 Sheffield Dementia Action Alliance Ideas for initiatives and how the Alliance can keep in touch with people with dementia and family carers: 1<sup>st</sup> December 2016

- 9) SHINDIG 19: Advice to NHS and social care taff on gathering feedback from people with dementia and their family carers/supporters: 1<sup>st</sup> December 2017
- 10) Complaints Annual Report 2016/17 Sheffield Health and Social Care (SHSC): April 2016 to March 2017

### 3 Findings

#### 3.1 What are the positive effects of accessing dementia services?

#### 3.1.1 Getting a diagnosis and information

Receiving timely diagnosis and information to help them understand their own, or their loved one's condition, was identified as one of the things that people found most important.

People describe waiting for a diagnosis as very distressing, particularly family carers, but once a diagnosis is made, there is a sense of relief. Receiving information about the condition and the support available can provide some reassurance about the future.

"We were given some excellent advice which really helped us to plan for the future. The consultant was warm, professional and encouraging. She was empathetic and related well to our situation"

- FFT Memory Clinic - May 2017

It's important to people that information is presented in a way that they can understand and that it's organised well so that they do not become overwhelmed.

"At memory services people are often given too many bits of information and it can be confusing and overwhelming. Would be good to simplify the information given, e.g. a checklist of all leaflets available, so could choose which ones to read first.

 SHSC Involvement and Engagement of People with Dementia Roadshow – October 2017 Peer support is identified as important to patients, families and carers across all themes and this includes sharing information and advice, where carers said that meeting other carers is a good way for them to get information.

## 3.1.2 Accessing social activities reduces isolation of people with dementia

Social activities for people with dementia are considered to be important for reducing loneliness. People said that they feel more comfortable socialising in environments where dementia is normal. This helps them to relax and have fun and, importantly, people felt that the stimulation provided by social activities can slow the deterioration of symptoms.

"These days [at the centre] have proved a life line - she has food, company, outings and since her attendance, her Alzheimer's, managed via additional medication has not progressed to any further level. She has become much more sociable and can interact in a positive way"

- Consultation on the proposed Changes to Dementia Services at Hurlfield View and Stocksbridge – November 2016

It can be very disappointing for people when social activities change, come to end or are inaccessible. Family members felt strongly that activities are not only essential for keeping people with dementia stimulated, but also to their ability to care for relatives

"My father in law when assessed was told he would be upstairs in the home during the day so he could socialise with others, but on a night they only had a bed downstairs on the dementia unit. He made friends upstairs where more social activities took place. After three days because he could not walk very well staff stated he was better off downstairs with very limited social activity. Best for staff not patient."

- Healthwatch Sheffield Rate and review - Seven Hills Nursing Home - 18<sup>th</sup> February 2018

#### 3.1.3 It enables you to stay at home or near home

Good dementia care supports people to stay at home. People feel it is important to be around familiar things like their home, garden and neighbourhood and to stay with, or near to, their close friends or relatives.

"Alzheimer's is a cruel thing. It takes any sense I had. It has changed my outlook on life. I accepted that I was going to finish up in a home somewhere but with the home care I am able to stay at home. I can see the gardens and I can stay near my neighbour who I like"

- Healthwatch Sheffield Experiences of Home Care - March 2018

People would like to be able to access care close to home. Services should be easily accessible by public transport or have transported provided.

"The tea dances were good, but it was difficult to get a place and they might be better also offering them more locally than just in the City Centre."

- SHINDIG 15 – December 2016

# 3.1.4 Respite for family carers allows them to carry on caring for people at home

Day centres, home care and social groups, such as dementia cafes, provide opportunities for carers to get some respite from their caring commitments. They use this time to rest, see friends or do some shopping. Ultimately this allows them to continue caring for their loved one at home.

"I would be a prisoner in my own home without it"

- Consultation on the proposed Changes to Dementia Services at Hurlfield View and Stocksbridge – November 2016

Carers also describe how knowing that their relative is being cared for well is a huge relief, reducing their stress levels and enabling them to provide better for their loved one.

"Since mum was admitted to G1 at Grenoside Grange she has been cared for very well. Staff are all attentive and caring. It has brought some relief and reassurance"

Care Opinion – 21<sup>st</sup> September 2017

#### 3.2 What makes a service good for people with dementia?

Feedback gathered from people with dementia and their family carers generally shows people to be positive about the services they receive. For example, 98% of respondents said they would 'strongly recommend' the memory clinic when responding to the Friends and Family Test (FFT) between April 2017 and March 2018.

#### 3.2.1 Friendly staff

Staff attitudes and behaviours are consistently identified as being key to good experiences of care. Specifically, being friendly, reassuring, understanding and kind puts people with dementia at ease and enables them to benefit from the service they are accessing. People with dementia also really valued being treated with dignity and respect even though they might struggle communicating with staff. A good sense of humour was also consistently identified as being important.

"All the staff were welcoming, friendly, helpful and informative. You all deserve a gold medal"

- FFT Memory Clinic - July 2017

"My Mum has just spent 5 weeks on G2. She has late stage dementia which presents difficulties in most areas of care. I want to praise and thank all the staff on G2 that have been involved in my Mums care. They treated my Mum with dignity and respect, they were very caring and understanding regarding all her needs. She received fantastic care and support. What a great hospital and wonderful staff. I can't thank them enough."

- Care Opinion – 18<sup>th</sup> February 2018

"It was with great anxiety that we brought [my father] to Birch Avenue. However, within a very short period of time, our minds were put to rest. From the moment that we looked around the home, the sincerity of the staff was obvious. We were greeted kindly by everyone that we met including managers, nurses, support workers and domestic staff and were welcomed and guided around the home by John. My father was never going to settle easily, but with great patience and understanding, staff gradually made him feel at ease. Although he was always able to remember his 'real' home in Gleadless, he did come to accept Birch Avenue as his home and the staff as his friends."

- SHSC Annual Complaints report - April 2017

"The Rapid Response Team was absolutely brilliant, we really appreciated everything you did and how you treated mum like a human being and an individual. Sounds simple but not everyone we've encountered has done that."

- SHSC Annual Complaints report - April 2017

#### 3.2.2 Time and flexibility

Being given enough time is considered to be very important. People with dementia need time to compose their thoughts and explain things. They really appreciate it when staff are patient with them and appointments are long enough.

"Staff need to give us more time to understand and gather our thoughts."

- SHINDIG 19 – December 2017

"Dr [] gave us plenty of time during dad's appointment. She listened carefully to all the background information about dad. We asked her lots of questions and at no time did we feel rushed at all, she was very patient, caring and professional throughout"

- FFT Memory Clinic – May 2017

People feel value services that are flexible and responsive to a person with dementia's individual needs.

"My mother has mobility issues and has dementia. She required significant dental work and the staff [at Charles Clifford Dental Hospital] were all unfailingly helpful and spent time explaining what was happening and making sure she was happy. She couldn't cope with

all the work in one go so the appointment staff managed to sort out another appointment that fitted in with my diary on the spot rather than having to ring up and book from scratch."

Healthwatch Sheffield Feedback Centre - 18<sup>th</sup> August 2016

#### 3.2.3 A calming environment

A calm and welcoming environment was seen as important in preventing people with dementia feeling overwhelmed or confused. The environment should be quiet and comfortable with welcoming staff.

"My husband and I took my mother to this specialist clinic. She suffers from anxiety and dementia. We were treated with great kindness and understanding. The atmosphere was very calm and friendly. We would like to thank [the staff team].

Healthwatch Sheffield Feedback Centre - Heeley Dental Clinic - 2<sup>nd</sup>
March 2016

"Welcoming environment, not too long await before appointment time. Easy parking for disabled and welcome cup of tea."

- FFT Memory Clinic - August 2017

"We've just found out that the recommendation is for enhanced care in a nursing home after discharge from G1, which is really sad but practically the best thing and [Mum] is experiencing the world in a much gentler, calmer, happier way as a result of the care that she has received there. It's the best we could have hoped for."

- SHSC Annual Complaints report - April 2017

## 3.2.4 Including people with dementia in making decisions about their own care

A recurrent theme is the importance of including people with dementia in decisions about their own care. This is an essential part of being treated with dignity and respect.

"My Dad has dementia and his Dr is very good at involving him in decisions to do with his on-going care"

- Care opinion – Crookes practice - 30<sup>th</sup> October 2017

However, people feel that this needs to be done carefully and sensitively, taking into account the level of response a person with dementia can give.

For example, sometimes when people with dementia are asked what they would like to do they might refuse to be washed, to get out of bed or to eat. Family carers have said that this sometimes leads to inappropriate care of their loved one. They would like their relative with dementia to be asked but they would also like staff to make sensible decisions being mindful of each individual's ability to make choices about their own care.

"My mum has early signs of dementia but it still able to carry out basic functions for herself, although she does at times need prompting, and is forgetting to cook her microwave meals. We have asked them directly & through the service providers on more than one occasion to give her an evening meal and not ask her because she tells them she will get something later but she is not because all the ready meals we are buying are still in the freezer."

 Healthwatch Sheffield Feedback Centre - Direct Health – 16<sup>th</sup> March 2018

# 3.2.5 Using a range of engagement methods to get feedback from dementia service users and their carers

Listening to the views and experiences of people with dementia is considered to be important although it can be difficult to do well.

The preferred time to give feedback about services is at the time of accessing the service or immediately after. Face to face feedback is favoured and, if verbal communication is difficult, observations of body language and facial expressions can play an important role in understanding how someone with dementia is feeling.

Group discussions in a social and relaxed atmosphere are good for gathering experience and inviting people's views (for example, during engagement and consultation). Speaking to people in a familiar environment such as a day centre or at home was also identified as being a positive way of helping someone with dementia to feel comfortable enough to share their story.

There was no one way that everyone felt was good for collecting feedback from people with dementia in all circumstances. It was felt that a number of different approaches and settings need to be used to allow people to participate in a way they find comfortable.

### 3.3 What are the gaps in the evidence?

Below we have identified some areas that do not seem to have been covered in detail in previous engagement activities, or captured in recent feedback.

These topics could be investigated in more detail and we recommend that Sheffield CCG consider carrying out a full gap analysis in the context of the objectives of the dementia improvement plans in order to identify any other areas that need further evidence.

For each area we have identified we have provided an example of relevant background information (this will not be local or exhaustive).

Several organisations have captured experience data at a national level, including:

Dementia Services: Findings from the network

https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/dementia services - findings from the healthwatch network 0.pdf

Alzheimer's Society Engagement and Participation

https://www.alzheimers.org.uk/info/20105/engagement and participation

#### 3.3.1 Aspects of the carer experience

Many people with dementia are supported by relatives who live outside of the city. Engaging with them might help to understand what can be done to help them care for their relative from a distance.

The experiences of carers who are in employment are not well described, as well as the role that employers play in providing support (or not) and the potential financial consequences of having to leave work or reduce hours to care for a loved one.

The CCG may wish to explore further what can be done to support carers maintain their own wellbeing.

For further information:

Social Care Institute for Excellence resources on Carers of people with dementia. <a href="https://www.scie.org.uk/dementia/carers-of-people-with-dementia/">https://www.scie.org.uk/dementia/carers-of-people-with-dementia/</a>

# 3.3.2 Experiences of BME (Black, Minority, Ethnic) patients, families and carers

Generally the experience data does not include ethnicity information; the exception being the Memory Clinic FFT. From those who answered this question between April 2017 and March 2018, 97.7% of people identified as white. This compares to 81% of Sheffield population according to the 2011 census.

Although this disparity is may be partly due to the age profiles of Sheffield's ethnic groups, risk factors for dementia are more common in Asian and Black Caribbean communities.

Based on national experience evidence data, we recommend that the CCG actively seeks the views of BME people when reviewing people's experiences of dementia services.

For further information:

Dementia does not discriminate: the experiences of black, Asian and minority ethnic communities

All-Party Parliamentary Group on Dementia. (2013). London: All-Party Parliamentary Group on Dementia.

This inquiry report from the All-Party Parliamentary Group on Dementia brings together evidence and understanding about the experience of people with dementia from the black, Asian and minority ethnic (BAME) community.

https://www.alzheimers.org.uk/download/downloads/id/1857/appq 2013 bame r eport.pdf

#### 3.3.3 Effect of co-morbidities and/or sensory impairment

Many people with dementia have other medical conditions that may impair their ability to engage. It would be valuable to put an extra effort to investigate how these people engage with services.

For further information:

The University of Manchester is working with Deaf people to record their experiences of living with dementia:

http://research.bmh.manchester.ac.uk/deafwithdementia.

#### 3.3.4 Young onset dementia

Engagement specific to patients, families and carers experiencing young onset dementia have not been captured locally.

For further information:

Young Dementia UK has captured people's stories on their website:

https://www.youngdementiauk.org/living-young-onset-dementia

### 3.3.5 A whole person/whole system view

Much of the readily available local experience data is focused fairly narrowly on existing services (e.g. a particular ward or a particular element of care).

Considering the scale and ambition of the CCG's improvement programme, there may be benefits to involving people in a wider sense, for example to capture

people's views on social factors such as housing, the role of funding, technology, prevention and co-ordination of care.

Involvement approaches such as co-production allow for more open, person centred explorations of experiences, but require a significant commitment.

#### For further information:

The Dementia Engagement and Empowerment Programme (DEEP) is a growing user movement across the UK:

https://www.jrf.org.uk/report/developing-national-user-movement-people-dementia