

Appendix 4

Organisations contributing to the development of *Living Well With Dementia in Leeds*.

Leeds Integrated Dementia Board

Representatives from Leeds Alzheimers Society, Advocacy for Mental Health and Dementia, Carers Leeds, Leeds Older People's Forum, Volition (mental health network), 8 clinical leads and managers from the three Leeds NHS trusts (LCH, LTHT, LYPFT¹); Chief Officer and Head of Commissioning, adult social care; Clinical Director, NHS Leeds North Clinical Commissioning Group; Specialist Palliative Care Services.

Leeds dementia event, May 2012

Event addressed by Christine Bailey, a person living with dementia.

Workshops at the event included:

- Dementia-friendly Leeds: led by Dementia Without Walls (York), with Joseph Rowntree Foundation, Leeds Alzheimer's Society, NHS Leeds Public Health.
- Staying safe and secure: led by Leeds City Council, with West Yorkshire Trading Standards, Neighbourhood Watch Otley, Care and Repair Leeds, West Yorkshire Fire and Rescue
- Early diagnosis and support: led by LYPFT Memory Services; Leeds City Council Peer Support Service; person living with dementia.
- Supporting carers: led by Leeds City Council carers' commissioner, Carers Leeds, Shared Lives Leeds.

Event attended by:

- 22 staff from adult social care
- 19 staff from independent sector care providers
- 27 neighbourhood network and third sector organisations
- 16 staff from NHS organisations.
- 5 people with dementia or carers.

Consultation on draft, July – Sept 2012

Written contributions:

- 8 short online questionnaire responses from family members / carers.
- 6 long online questionnaire responses from staff.
- Leeds Older People's Forum
- Advocacy for Mental Health and Dementia

¹ Leeds Community Healthcare NHS Trust; Leeds Teaching Hospitals Trust; Leeds and York Partnership Foundation Trust.

- Combined response from Armley Helping Hands, Bramley Elderly Action, Farsley Live at Home Scheme, Pudsey Live at Home Scheme, Stanningley and Swinnow Live at Home Scheme.
- West Yorkshire Fire and Rescue Service.
- Specialist Palliative Care Services.
- NHS Leeds Continuing Healthcare;
- Leeds Integrated Health and Social Care Programme lead.
- Social business event: current and potential service providers.

Meetings / events:

- LCC Adult Social Care Scrutiny Board
- Leeds Community Healthcare lunchtime seminar.
- Leeds third sector networks event, attended by: Advocacy for Mental Health and Dementia; Leeds Alzheimers Society; Anchor, Burmantofts Senior Action; Carers Leeds; Chapel Allerton Good Neighbours; Community Links; Health for All; Leeds Black Elders; Leeds Housing Concern; Leeds Irish Health and Homes; MAE Care; Neighbourhood Action in Farnley, New Farnley & Moor Top; OPAL (Older People's Action in the Locality); Relatives and Residents Association Leeds Branch; Shantona; Sikh Elders Service; Stanningley and Swinnow Live at Home Scheme; United Response; Leeds Library and Information Service.

Further meetings

- Dementia focus group – including clinical commissioners from all 3 Leeds CCGs; NHS Leeds; Leeds City Council adult social care; clinical leads from all 3 Leeds NHS provider trusts; Leeds Alzheimer's Society; Community Links; Integrated Health and Social Care Programme.
- Carers Leeds / carers commissioners.

Feedback which influenced the strategy:

- National statistics may underestimate dementia prevalence linked to health conditions such as diabetes and high blood pressure, in more deprived areas and some BME communities.
- People are experiencing very long waiting times for memory services in some areas of Leeds.
- Service provision should not depend upon diagnosis, because of the barriers to diagnosis and in particular the needs of families and carers for information and support pre-diagnosis.
- The need for information, eg. a "tube map" of the 'dementia journey' and services.
- The importance of sustaining and supporting carers; the difficulties carers have in remembering one's own needs, when having to speak up for the person with dementia.
- Receiving a diagnosis is very difficult, but sometimes life has already become very difficult before diagnosis, and it is the starting point for life to improve.

- Bereavement support for families / carers.
- Concern that policy priorities will lead to an increase the numbers of people diagnosed without then offering post-diagnosis support. Therefore local investment is needed.
- The 'third sector' has a key role at all stages of the "dementia journey", is already doing a lot, and is keen to develop services. Support is needed to involve people with dementia in 'mainstream' activities and services, eg. training for staff and volunteers.
- Consistent standards of support, and integration of health and social care are essential.
- The idea of "rights, risks, choice and control" to encompass the personalisation of care services, support for decision-making and potential impact of improving access to advocacy.
- Activities and occupation must not be seen as "extras" over and above basic care, they are essential to avoid boredom, frustration, "sat staring into space all day".
- Strategy document is helpful, but it needs an action plan / specifics / timescales.
- The strategy document is quite long, but people appreciated the information / description of local services.