Appendix 2

LIVING WELL WITH DEMENTIA IN LEEDS

Our local strategy 2013-16

1 Foreword

Recent years have seen the National Dementia Strategy (2009), The Prime Minister's Challenge On Dementia (2012) and many other publications setting out a positive vision to transform health and social care for people with dementia. If people with dementia have earlier diagnosis leading to better information, support and treatment, then more people will stay well for longer, and have less need for admissions to hospital and care homes.

Local services in Leeds have been among the pioneers of many important developments, including memory services; specialist services to support people with dementia in hospital, and to return home from hospital; peer support; dementia cafés and activities offered by voluntary and community groups. However, there is a great deal more to do, to improve awareness, diagnosis and support; to ensure dementia is considered alongside other health conditions and needs, not in isolation; and to develop the workforce to provide person-centred care.

Change must go beyond health and social care, into our everyday lives. We can achieve a 'dementia-friendly' Leeds - the city, and our towns and villages - by listening to people's experiences, and working together to make changes.

This strategy gives an overview of local services and states our local priorities for the next three years. It goes with our action plan which sets out what local organisations are doing, and will do, to improve quality of life and quality of care, with people with dementia, families and carers.

Notes and explanations

If you are reading this document on a computer, then words which appear in blue should work as "hyperlinks" – if you are connected to the internet, clicking on these words will take you to eg. the relevant publication or website. These links were correct at the time of writing, but if the publisher has changed the website, you might need to do an internet search for the material.

If you are reading the paper document, then these words will appear as blue text or grey, depending on the print-out. If you are interested in the relevant document or information but do not have internet access to search for it, then please contact Tim Sanders (details below).

Where this document uses technical terms and jargon, it is explained in the text. The following definitions may be useful:

Adult social care	Services which help with eg. personal care, meals, daily living and social life; or assess the need for these services. In Leeds, these may be funded, arranged or provided by Leeds City Council.
Community health services	Services such as community nursing ("district nursing") which see people at home or in local clinics. In Leeds, these services are usually provided by Leeds Community Healthcare NHS Trust (LCH).
GP	Your doctor, or "General Practioner".
Primary Care	Health services, such as your GP, who are the first point of contact with any medical concerns. Most GP practices employ other staff eg. practice nurses to provide some services.
Secondary Care / Specialist Care	Health services which we usually access by a referral from our GP, eg. hospital treatment. In Leeds, the main providers are Leeds Teaching Hospitals Trust (LTHT); and Leeds and York Partnership Foundation Trust (LYPFT) as the provider of mental health and learning disability services.

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The term 'recovery' has developed a specific meaning in mental health. It has been defined as: *'A deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life, even with limitations caused by the illness…'*

W.A. Anthony, 1993, quoted in the national strategy No Health Without Mental Health.

The artwork in this document is from The Living Story project, led by West Yorkshire Artlink, working with people with dementia who were inpatients at Asket Croft and The Mount in Leeds, and staff from those units. The project was funded by the Evan Cornish Foundation. Further information and a book from the project are available from West Yorkshire Artlink http://www.artlinkwestyorks.org/projects.php

Front cover by May
Back cover by Rhoda
'Cup of tea' by Marjorie
'It's one of those days' by Jan and Angela
Red, pink, yellow, green, blue abstract by Victor

Hand massage photo by Tara Greaves, from Leeds dementia event, May 2012.

1 Introduction

> Once you have met a person with dementia, you have met one person with dementia
>
> *Tom Kitwood*

1.1 Dementia can be defined as:
….a set of symptoms which include loss of memory, mood changes, and problems with communication and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer's disease and damage caused by a series of small strokes.

Dementia is 'progressive', which means the symptoms will gradually get worse. How fast dementia progresses will depend on the individual person and what type of dementia they have. Each person is unique and will experience dementia in their own way…

Alzheimer's Society Factsheet, What Is Dementia?[1]

The risk of developing dementia increases with age, and the condition is becoming ever more prevalent as we live for longer and the balance of the population shifts towards more older people. As individuals, dementia is a disabling condition which we fear, for ourselves and our loved ones. As dementia becomes an ever-higher priority, we have the opportunity to enable more people to live well with the condition.

1.2 One purpose of a strategy is to bring people and organisations together to work towards a shared vision. This strategy describes how we want Leeds and its local services to be for people living with dementia. This includes family members and other carers. Our vision for Leeds is that:

> People and families affected by dementia will find that people are understanding and helpful, and experience excellent treatment and care, throughout the 'dementia journey'. We will work together so people can benefit from:
>
> - A voice for people living with dementia that influences local plans and services.
> - Living in a place which feels 'dementia-friendly'.
> - A helpful experience of early detection, diagnosis, and support, including honest and timely conversations about what to expect.
> - A health and social care workforce with the right approach, skills and understanding.
> - Treatment and care that works to keep people as well as possible, to plan ahead for the later stages of the condition, and to reduce admissions to hospitals and care homes.
> - Support throughout the dementia journey – timely access to help and advice when needed.
> - Equal and fair access to health and care services, overcoming the barriers that people with dementia often face.
> - The best possible experience of dying with or from dementia, with support when necessary from specialist palliative care.

[1] There are conditions defined as "dementia" which may not always be progressive, eg. some alcohol-related dementias can improve with treatment and abstinence from alcohol. This strategy is concerned with the progressive dementias, often associated with older age.

1.3 This strategy should help service providers to work together and plan; and inform local service providers to make investment decisions and design new services. It should enable local voluntary and community groups to apply for external funding with good evidence of local priorities.

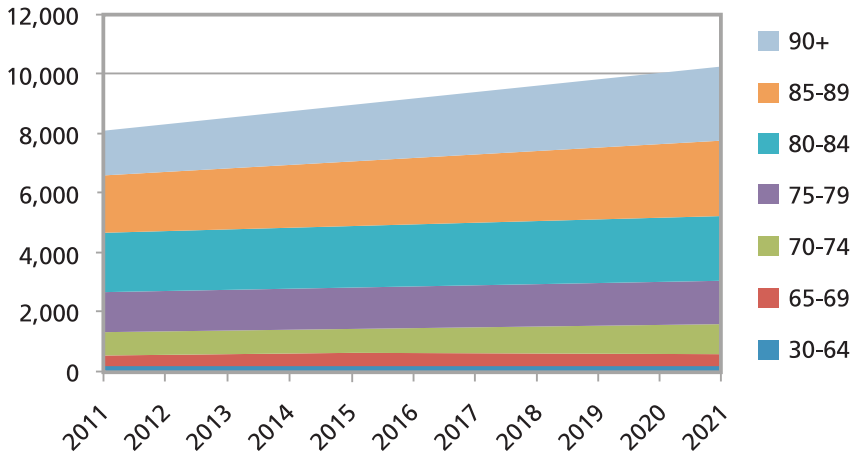
1.4 Older people in Leeds, as elsewhere, make huge contributions to social, community and economic life in the city, our towns and villages. Older people contribute in many ways, for example as leaders, grandparents, volunteers, unpaid carers. As we grow older, we might wish to continue with activities that we've always enjoyed, and we might wish to try out new activities, adapting to changes and taking advantage of opportunities. The Time Of Our Lives – Ageing Well in Leeds was launched in March 2012, and sums up our positive approach to later life in Leeds. This strategy aims to be part of that approach: honest and realistic about illness and loss, but continuing to value who we are and what we can do.

1.5 The Leeds Integrated Dementia Board is our local body which brings organisations together to set the strategy and co-ordinate action. Membership includes all local NHS organisations; Leeds City Council (Adult Social Care); the local Alzheimer's Society, Leeds Older People's Forum and other voluntary sector representatives and Leeds Care Association (private sector care providers). We wish to support and develop representation of people with dementia and carers.

1.6 This strategy comes at a time of pressure on public spending, when local authorities face severe cuts, and the National Health Service, although offered some protection from cuts, is still expected to find significant efficiencies to meet increased demand. We propose that supporting people early, will both lead to better quality of life and health, and reduce costs of more intensive care, such as admissions to hospitals and care homes. This fits with national and local policy for 'transformation' of health and social care.

1.7 There are an estimated 8,500 people with dementia in Leeds in 2013. This figure comes from research evidence which tells us how prevalent dementia is, applied to the local population figures . It is approximately 8% of the people aged 65 and over in Leeds. This is likely to increase, and estimated to become over 12,000 people with dementia in 2028 – a 35-40% increase in 15 years. These numbers conceal the great diversity of people with dementia and the effects it has on each individual. Some key facts and figures are shown in Box 1 and Figure 1:

Fig. 1: People with dementia in Leeds – by age band



[2]Population figures from Office of National Statistics *Interim 2011-based subnational population projections for England;* dementia prevalence by age from Alzheimers Society Dementia UK report (2007) .

BOX 1 – 8,500 PEOPLE WITH DEMENTIA IN LEEDS IN 2013

- Approximately 5,000 people of the 8,500 have Alzheimer's Disease; 2,000 have vascular dementia; the rest have mixed and rarer types such as frontal-temporal lobe dementia, and dementia with Lewy Bodies .
- approx. 52% of people with dementia in Leeds, have a diagnosis recorded on GP registers.
- Approximately 5,700 people of the 8,500 live at home, 2,800 in care homes.
- 200 people of the 8,500 are aged 64 and under.
- Nearly all of the increase in numbers of people with dementia will be people aged 85+, who are more likely to have other long-term health conditions, sensory impairments or to need some support with daily living.
- People with learning disabilities, especially Down's Syndrome, are at increased risk of developing dementia at a younger age.
- There are probably 100 – 200 people with dementia from each of the main black and minority ethnic groups in Leeds; older people of Caribbean, eastern European, Irish, Jewish, and south Asian origins.
- It is estimated nationally, that older people with dementia use 25% of all hospital bed capacity.
- 2,000 people every year experience new onset of the condition; perhaps 1,700 local people with dementia are in the last year of life.
- The more affluent and rural areas of Leeds have a higher proportion of the population with dementia, because there are more older people in these areas.
- However, the risk of dementia at any given age appears to be higher in urban areas with higher deprivation. This may be because vascular dementia is linked to high blood pressure, diabetes and heart disease. Older people of south Asian and Caribbean origins may therefore also be at higher age-related risk of dementia.
- Therefore, national prevalence figures may be an underestimate for some communities within Leeds.

1.8 How dementia affects the person depends on an individual's life-history, relationships and psychology, alongside the progress of dementia and other health conditions. One size does not fit all for people with dementia. Therefore, health and social care policies which promote 'personalisation' offer opportunities for better care and support.

1.9 A simplified model of the 'dementia journey' is shown on the following page. It is intended to help us think about what we have working well in Leeds, and what is missing. The rest of the document considers the stages of this journey, together with key themes such as families and carers; workforce; care homes and hospital care.

Priority

A "Dementia Needs Assessment" for the Leeds population will improve our knowledge and understanding of local need and current use of services. This information will be part of wider population needs assessment work regarding long-term conditions, and the needs of older people.

[3]Further information about dementia can be found from the Alzheimer's Society, eg: http://alzheimers.org.uk/Facts_about_dementia/What_is_dementia/

The 'Dementia Journey' in Leeds
A way to think about living well with dementia

Awareness, diagnosis and early support

- Prevention of dementia where possible.
- People in Leeds will be aware of the signs and symptoms and feel able to seek help.
- GPs respond consistently to assess memory problems.
- GPs and memory services work effectively to provide timely and supportive diagnosis.
- Sustain and improve annual increase in people diagnosed on GP registers, with diagnosis occurring at an early stage of dementia.
- Help, advice and explanation to overcome the barriers to diagnosis.
- Good information about dementia and the services available.
- Consistent and clear access to post-diagnosis support, treatment and review.

Well-being + person-centred care

People with dementia, families and carers will feel respected and valued, with:

- Leeds feeling like a "dementia-friendly" place.
- a positive response to individual abilities, likes and dislikes, and life history.
- support to ensure meaningful activity and social engagement.
- practical and emotional support to prepare and plan for the later stages of dementia, including advance care planning.
- self-directed support, to regain and remain in control of daily living.
- understanding and support with emotional and psychological needs.
- recognition of and treatment for health needs; access to routine checks; not assuming every symptom is because of dementia.
- support for individual rights and decision-making, including access to advocacy.

End of life care

- Carers, clinicians and other staff will have information and support to recognise the end-stages of dementia.
- We can have honest conversations and draw on earlier plans for a 'good death'.
- Recognition and treatment of pain, nausea and other symptoms.
- The right care and support will be available at one's preferred place of death, avoiding unnecessary admissions.

2 Awareness, diagnosis and early support

It's vitally important to get the diagnosis early because at least then you can try to sort out your future.

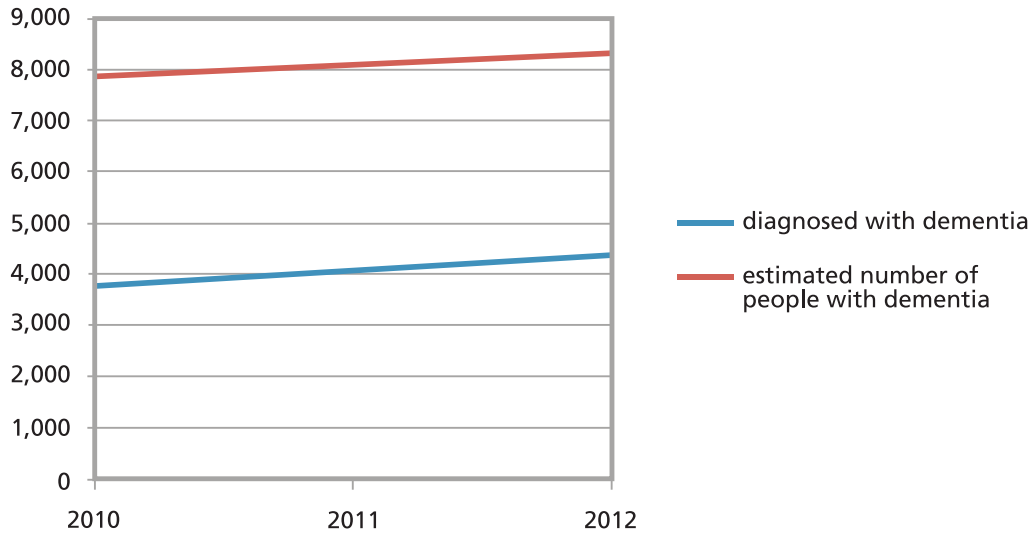
Agnes Houston, person with dementia and Chair of Scottish Dementia Working Group

Overview

2.1 It is likely that dementia is often undiagnosed, or diagnosed at a relatively late stage. The "diagnosis rate" is the number of people actually recorded on GP registers with a dementia diagnosis, divided by the estimated people with dementia in the population (the estimate is made as described in the previous section). At March 2012, the estimated diagnosis rate for Leeds was 52%, slightly above the national and regional rates, but still leaves 4,000 local people with dementia who do not have a diagnosis.

2.2 Nationally and locally, diagnosis rates are generally increasing, adding about 2 percentage points year-on-year. Any trend will be clearer when we have March 2013 figures. Full national data is available from the Alzheimer's Society "Mapping The Gap"[4].

Figure 2: Leeds - Comparison of estimated numbers of people with dementia, with actual numbers on Leeds GP practice dementia registers.



2.3 It can take a long time before help is sought for concerns about possible dementia. Colleagues who work in Doncaster memory services have found from interviewing patients, that it may take a year to share concerns within the family, and a further year to talk to a health professional.

[4] Please note that the 2011 Census shows Leeds has fewer older people than previously estimated, and at time of writing (March 2013) Mapping The Gap is yet to be updated, and therefore has a slightly lower figure for Leeds diagnosis rate.

2.4 There are conditions that can present in a similar way to dementia, but actually be treatable – for example under-active thyroid; sometimes depression in older people can cause forgetfulness and confusion. Therefore, the assessment process for diagnosing dementia, can discover other conditions which can be treated, and save some people from living with an incorrect belief about having dementia. Conversely, dementia may not always first present as memory and cognitive problems – depending on the type of dementia and part of the brain affected, it may present with behaviour changes, poor balance, or low mood. It is a complex condition, and initiatives to improve awareness and detection have to take this into account.

2.5 Therefore, public awareness is very important to encourage and support the first steps to seek help and diagnosis. There are barriers of fear; lack of understanding; myths around dementia, old age and mental health. Awareness campaigning should address these attitudes and barriers as well as providing information; and be well-designed with messages and methods appropriate to the diversity of Leeds.

She'd ask me to do something and then find I hadn't and she'd play pop with me but I'd be swearing blind she hadn't asked in the first place. It was causing a bit of tension between us, a bit of a rift that wasn't there before. I thought she was imagining it….

….The diagnosis of dementia is just saying that you've got a certain illness and then you learn to cope with it and make the most of your life. People don't know what dementia is and it's a bit scary at first….

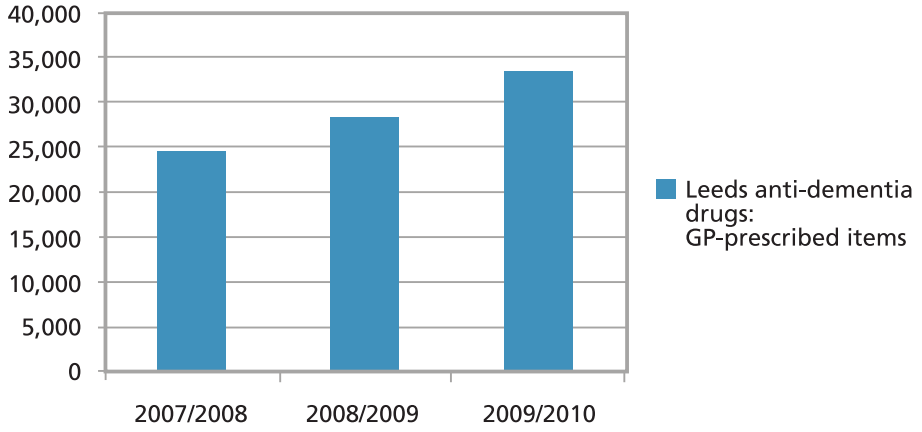
… Slowly, I found I was becoming more confident and positive, learning coping strategies and picking up things. It has grown from there and now my life has completely changed and I think I've got an amazing life.

Bob, person with dementia and member of Leeds peer support network

2.6 General Practitioners (GPs) are often the first point of contact for people concerned about possible dementia. The process may involve discussion of concerns with the person and family; a short cognitive test; and screening for other possible conditions. The GP may then refer on to a specialist memory service ("memory clinic" or "memory assessment") for further investigation and diagnosis, and follow-up treatment and support if dementia is diagnosed. In Leeds the memory service is provided by the Leeds and York Partnership Foundation Trust (LYPFT). Leeds residents living near the local authority boundary might be referred to neighbouring services eg. at Knaresborough for people with GPs in the Wetherby area. People with learning disabilities who develop possible symptoms of dementia may require a specialist service. This is provided by LYPFT from the Community Learning Disability Teams, working with colleagues in old-age psychiatry and memory services as required. (NB. LYPFT is developing a single 'pathway' for cognitive assessment which will take account of specific needs).

2.7 Following diagnosis, the memory service provides information, advice and support, either directly or via its links with Leeds Alzheimer's Society and other local services. The service offers "memory groups" to people diagnosed with dementia and families / carers, which include information, practical coping strategies and adjusting to having the condition. The service provides Cognitive Stimulation Therapy (CST), a series of sessions to stimulate and engage people, and offer the social benefits of a group; however, the number of CST groups is variable. There may be prescription of anti-dementia drugs. These can, for some people with Alzheimer's Disease, improve or slow the progress of symptoms. Benefits are less certain for other types of dementia, and at present there are no equivalent drug treatments for vascular dementia. The memory service is currently responsible for follow-up and review for people prescribed these drugs.

Fig. 3 shows the increasing prescription of anti-dementia drugs in Leeds.[5]



2.8 In 2011-12 the memory service saw 2,145 people, either for assessment / diagnosis (including people who turned out not to have dementia), or for follow-up. This is approximately 50% of the people in Leeds diagnosed with dementia, and 25% of the estimated number of people with dementia in the local population.

2.9 There are a range of services in Leeds, which help people with dementia and carers to "live well" with the condition. Sometimes this kind of support is referred to as "self-management" for a long-term health condition. Local services include:

- Dementia advisers, employed by the Leeds Alzheimer's Society.
- Carer support workers and carer support groups, provided by Carers Leeds and Leeds Alzheimer's Society.
- Peer Support Network, run by Leeds City Council.
- Dementia cafés, run by Leeds Alzheimer's Society, Carers Leeds and Leeds Neighbourhood Network Services and other community organisations.
- A range of activities, including intergenerational work and creative arts run by the Neighbourhood Networks and other groups.

2.10 Some services which support people after diagnosis, can also play a valuable role before diagnosis, helping to discuss concerns, explain the next steps and practical support to attend appointments. A listening ear and some advice could help a concerned family member of a person who appears to be developing memory problems, but does not seem to acknowledge them. This means that such services should take a flexible approach, and not depend rigidly on a diagnosis of dementia as a condition of offering help. For people who live alone, community groups might be the first to notice that possible signs and symptoms of dementia are developing.

2.11 There are several initiatives which introduce incentives to improve detection of dementia. This is because people with undiagnosed dementia may well have other long-term conditions, and are at particular risk of coming into services when there is a crisis, illness or injury. The 'national dementia CQUIN' for acute hospitals incentivises the screening and assessment of people aged 75+ who have emergency hospital admissions (CQUIN is short for Commissioning for Quality and Innovation). Further information

[5] From Leeds Mental Health Needs Assessment, 2011

is at section 9 of this document, The Right Care – people with dementia in hospital. A further local CQUIN in Leeds will (from April 2013) incentivise community health teams to identify people with dementia. The national NHS 'General Medical Services' contract with GPs for 2013-14 will include screening for dementia as a "Directed Enhanced Service".

2.12 Awareness raising about dementia and services is planned as part of the "NHS Healthcheck" initiative. The Healthcheck is aimed at adults aged 40 – 74, with dementia awareness promoted for the 65-74 age group.

2.13 The early stages of dementia can be an opportunity to prepare for the later stages. Family, friends and professionals can help by prompting timely and honest conversations. There will often be opportunities to notice and respond to the natural concerns that people have about the future. Examples include making a Lasting Power of Attorney, which can cover both financial arrangements, and preferences for future care and treatment.

What we need to improve

The benefits of dementia awareness, early diagnosis and support include:

- Detecting conditions that are not dementia, but which can present in a similar way, and can be treated.
- The opportunity to be prescribed anti-dementia medication for Alzheimer's Disease and some other types of dementia.
- The opportunity for non-drug treatments such as cognitive stimulation therapy.
- The opportunity to have useful information, support and to take part in activities.
- The opportunity to prepare and plan ahead.
- To sustain and recover social life and friendships.
- People are more likely to get to know important information and access other services.
- Family / carers can have a break, someone to talk to and get useful information.

2.14 Clinical Commissioning Groups (CCGs) must set a "target trajectory", the ambition for increasing dementia diagnosis over the next two years. This is part of the NHS Outcomes Framework, and CCG Outcomes Indicator Set (January 2013). The three CCGs in Leeds are aiming, as a minimum, to sustain an annual 2.5 percentage point increase in the diagnosis rate.

2.15 There appears to be variation in the understanding that GPs have of dementia and the 'pathway' for diagnosis, treatment and support. A National Audit Office survey published in 2010 showed only 47% of GPs agreeing with the statement that; *I received sufficient basic and post-qualifying training to help me diagnose and manage dementia.* The Leeds Clinical Commissioning Groups (CCGs) have organised GP training sessions on dementia in late 2012, as part of the "Target" programme. Further education and support will be considered to improve knowledge and develop consistent practice for their GP members, including the use of practice-by-practice data to see where it is most needed.

2.16 The Leeds memory service reports (October 2012) that waiting times from referral to first appointment are 6 – 18 weeks. The Department of Health has published a model service specification which is not compulsory, but suggests that 3 weeks from referral to first appointment should be the aspiration.

Clinical staff suggest that waiting times could be reduced if time could be used more for new patients, and less for routine reviewing with people prescribed anti-dementia medication.

2.17 There are a range of initiatives and innovations with potential to improve the effectiveness of the diagnosis "pathway" eg:

- public awareness of signs and symptoms; what to do if you are concerned; clear messages about the benefits of seeking a diagnosis and the help you will be offered.
- more diagnosis in primary care settings, and other accessible places eg. memory services running clinics in different places, GP diagnosis of severe dementia.
- GPs reviewing patients who may be at higher risk of dementia.
- GP practices checking that diagnosis of dementia is recorded correctly and that people with dementia and carers are invited for review.
- Leeds Teaching Hospitals Trust to work more closely with memory services on brain scanning.
- review "shared care" arrangements for anti-dementia drugs, and the overall partnership between primary care and memory services.

2.18 Leeds has good services which offer post-diagnosis support, but there is not as yet a clear, consistent and guaranteed standard of support for people with dementia and families.

2.19 This part of the 'dementia journey', from awareness through diagnosis to early support, requires a co-ordinated approach. People are more likely to understand the potential to live well with dementia, and understand the benefits of seeking diagnosis, if there is a clear, guaranteed offer of treatment and support.

Priorities

- Local awareness campaign including innovative methods and messages for reaching diverse communities.
- CCGs to work with GP practices to improve training, and to identify and assess people with possible dementia.
- Reduce waiting times for the Leeds memory service, including short-term investment to address the longest waits for assessment.
- Review the local "shared care"arrangements for anti-dementia drugs.
- To review the Leeds 'pathway' for diagnosis from the experience of people with dementia and families, and make changes in response.
- To develop a Leeds model for post-diagnosis treatment and support, and a business case to develop and sustain it.
- To invest further in post-diagnosis support, for people living with dementia and families / carers.

3 Involving people and dementia-friendly Leeds

Each organisation is committed to the following principles:

- Ensuring that the work they do is planned and informed by the views of people with dementia and their carers, and showing evidence for this…

The National Dementia Declaration

Overview

3.1 Leeds has excellent examples of involving older people, people with long-term health conditions and carers in planning services. However, this is not an area of strength regarding people with dementia. It is important to support and develop local involvement and is part of our commitment to the National Dementia Declaration.

3.2 Leeds signed up in March 2012 to become a 'dementia-friendly' city, one of six announced at the launch of the Prime Minister's Challenge On Dementia. This will require a sustained approach over 1-2 years and beyond, working with the Dementia Action Alliance to define and achieve the standards set. At that same event, the Alzheimer's Society published the report Dementia 2012, including a national survey of experiences of living with dementia. Box 2 shows some examples.

BOX 2 – PEOPLE'S EXPERIENCES OF DEMENTIA

- 17% of people with dementia responding to the survey said that they are not living well with dementia at all, 55% said they are living quite well with dementia and only 22% said that they are living very well with dementia.
- 68% of respondents had a gap of longer than a year between noticing their symptoms and getting a diagnosis. 8% of respondents experienced five years or more from first symptoms through to diagnosis. (This could be caused by reluctance to acknowledge problems and seek diagnosis, as well as waiting for services).
- When asked if they lost friends after their diagnosis of dementia, 12% of respondents said yes, most of them, 28% said yes, some of them, and 47% said no. 4% of respondents reported that they haven't told their friends.

The top five solutions that people with dementia report could be done…:

- Better understanding of dementia and less social stigma attached (25%).

  People with dementia would like the following to have more of an understanding of dementia: family (54%), friends (58%), neighbours (51%), health and social care professionals (58%), people working in banks, post offices and shops (62%), the police (54%).
- More public awareness of the condition (17%).
- More local activities and opportunities to socialise (13%).
- More tolerance and patience from others (7%).
- More community spirit (7%).

Dementia 2012 report - Alzheimer's Society

3.3 The Dementia Friends initiative has been launched nationally, with the aspiration that by 2015, "we want there to be a million people with the know-how to help people with dementia feel understood and included in their community." This would be more than the population with dementia, and means some 15,000 'dementia friends' in Leeds.

3.4 The greatest barrier faced by people with dementia is probably stigma and negative attitudes to dementia. This probably arises from fear of the condition, misunderstandings and lack of knowledge. It is strongly linked to the attitudes and stigma faced by older people and people with mental health needs. Anecdotal local examples included a person being banned from a supermarket having forgotten to pay for some shopping; and a bus driver refusing to let someone on the bus, thinking they were drunk.

3.5 The physical environment is important, because dementia can affect the ability to understand visual and aural information and stimuli. Better lighting, clearer signage, and steps to reduce noise are becoming standard practice in care homes and hospitals, and could make a real difference beyond health and social care. Older people may have eg. sight and hearing loss as well as dementia, which exacerbates the difficulties. The tendency for shopping centres and supermarkets to be "branded" throughout the whole of their interior design, can, inadvertently, make important information blend into the background. We have a Leeds-based company, Find Signage, who supply the care sector with such signage, and belong to the Dementia Action Alliance. There is an opportunity to pilot dementia-friendly environment in eg. a local supermarket.

3.6 Leeds Library Services have already taken initiatives such as drop-ins at Pudsey and Armley Libraries, for people with concerns about dementia to seek advice. Libraries have resources for people to learn, take part in activities and have quiet space not far from busy centres in Leeds and local towns and suburbs.

3.7 The aspiration for dementia-friendly Leeds includes includes the city centre, inner city areas, and suburbs of Leeds itself; and the towns and villages within the local authority boundary. Any geographical community can sign up to work towards dementia friendly status, starting with involving local people to decide the priorities. A local initiative has started at Rothwell, to ask local shops and businesses to sign up, and to make good use of the local people who volunteer at the "Tea Pot" dementia café.

What we need to improve

- The benefits of developing and listening to the local voice of people with dementia, will be a well-informed approach to service development, in line with the principles of the National Dementia Declaration.
- The benefits of a dementia-friendly and aware Leeds, are that people will feel less stigmatised, more able to seek and find help, and be able to continue with day-to-day activities.

3.8 A local event was held during dementia awareness week on May 23rd 2012, with a strong emphasis on dementia-friendly Leeds. Leeds City Council's Chief Executive, Tom Riordan spoke about 'opening doors' with local business and transport services, and the Joseph Rowntree Foundation led a workshop discussion which shared learning from the "Dementia Without Walls" project in York. The initiatives proposed from this discussion were:

- Target a local supermarket to become dementia-friendly, including staff awareness, and practicalities such as seating. Since the event, Leeds Alzheimer's Society has made links and given awareness talks to local supermarket managers and staff.

- Intergenerational work; for example Bramley Elderly Action have worked with a local school to involve older people with dementia, in groupwork with children – sharing reminiscence, learning, playing games - at a local primary school.
- Consider a card or "passport", which can be shown as a way to obtain understanding and support.

3.9 People living with dementia have been involved in Leeds, in awareness-raising activity, and in saying what "dementia-friendly" Leeds might mean. However, there is not yet supported and systematic involvement of people and carers, to design and influence local services, or at Leeds Integrated Dementia Board.

3.10 Leeds City Council and Leeds Teaching Hospitals Trust have joined the Dementia Action Alliance at national level and in Yorkshire + Humberside. The Council's Executive Board have supported the formation of a Leeds Dementia Action Alliance, so that local businesses and organisations can sign up and commit to practical actions, however small.

Priorities

- Our local dementia awareness campaign (see previous section) to include messages that challenge stigma and encourage positive attitudes to dementia.
- The involvement of people with dementia and carers, properly supported.
- Start up the Leeds Dementia Action Alliance, and identify funding to run it effectively.
- Raise staff awareness and pilot dementia-friendly environments with local supermarkets, and transport companies.
- Develop more intergenerational work, eg. with local schools.
- Towns, villages and neighbourhoods to make a commitment to become dementia-friendly.

4 Integrated care and support for the dementia journey

Like many other long-term conditions, dementia presents challenges that require vigilance and co-ordinated working between health and social care.

Dementia Commissioning Pack, Department of Health, 2011

Overview

4.1 Dementia is a "long-term condition", defined as *health problems that require ongoing management over a period of years or decades* (World Health Organisation) or a *condition that cannot be cured but can be managed through medication and/or therapy* (Department of Health). It can cause our capabilities to change and decline over time, sometimes irreversibly because of the progress of the condition; but often reversibly, because a little support can make a great difference physically, psychologically and emotionally.

4.2 Dementia is much more likely to be found alongside other health conditions, rather than in isolation:

- In Leeds, 68% of people with dementia are aged 80 or over; and nationally, 55% of people aged 80+ have at least 3 long-term conditions.
- Data from Kent and Medway suggest that, of 1,350 people diagnosed with dementia, only 6% have dementia on its own; 60% have dementia with three or more other conditions.
- Data from Scotland suggest that 83% of people with dementia have at least one other long-term condition.

4.3 People with long-term conditions may require support from a range of health and social care services, including GPs and other GP practice staff (primary care); community nursing teams and roles such as community matrons (in Leeds provided by Leeds Community Healthcare NHS Trust); and specialist health services such as outpatient clinics. Long-term conditions may increase the risk of poor emotional, psychological and mental health. Health and social care organisations in Leeds are working together and investing in integrated management of long-term conditions. This approach is based on:

- Find Me – as well as diagnosis of conditions, an approach called 'risk stratification' helps to indicate who is most in need of support to prevent a deterioration in health and an increase in care needs;
- Enable Me – promoting "self-management", involving the person with the condition, family, community groups, and supported by staff;
- Support Me – integrated teams which work with people at the highest risk to well-being, to support health and social care needs.
- Decide with me, at all stages.

4.4 Leeds will be among the places piloting the "Year of Care" funding model in 2013-14, a new approach to funding services for people with long-term conditions. Dementia will be one of the conditions included in this approach.

4.5 It is important that people with dementia can benefit from these new approaches. However, people with dementia, families and carers tell us that advice and help is often difficult to find, not only at the initial stages of concern, but as dementia progresses. It can take a long time to find information and help, and life can be very difficult in the meantime.

4.6 The level of post-diagnosis support can be variable. A person with dementia who is prescribed anti-dementia drugs might stay with the memory service for some years, for medication review. However, this type of medication is not appropriate to treat vascular dementia; so the level of follow-up may differ. GP practices have an incentive to keep a register of patients diagnosed with dementia, and to carry out annual reviews with those patients, under the Quality and Outcomes Framework (QOF). But there is variation in how consistently this is done, and the format of the review. People diagnosed with dementia aged under 65, benefit from a specialist Younger Dementia Team as part of Leeds and York Partnership Foundation Trust.

> Of our older patients admitted with a hip fracture, many have dementia. Often this has never been diagnosed; and sometimes we find that the person had been diagnosed with dementia a few years ago, but hadn't had any support since then.
>
> *Consultant in medicine for the elderly, Leeds*

4.7 The Department of Health has proposed a service model in the Dementia Commissioning Pack (2011). It assumes clinical responsibility will rest with GPs, except during the formal diagnostic process and during acute admissions to hospital. It describes how GPs can be supported in this role via a service specification for dementia: better care at home, and in care homes.

4.8 The role of 'dementia advisor' has been piloted in 22 places around the country as part of introducing the National Dementia Strategy. Most areas which piloted the role have managed to sustain it, though the national evaluation is not yet published. Dementia advisor is not a qualified clinical role, but provides a named contact throughout the journey with dementia; someone who understands the system and how to refer and "signpost" on for further treatment, care and support. The Leeds branch of the Alzheimer's Society has created two part-time dementia advisor posts.

4.9 The following section, Families and Carers, refers to the model of Admiral Nursing, which is specifically a carer support role, providing advice and support throughout the dementia journey.

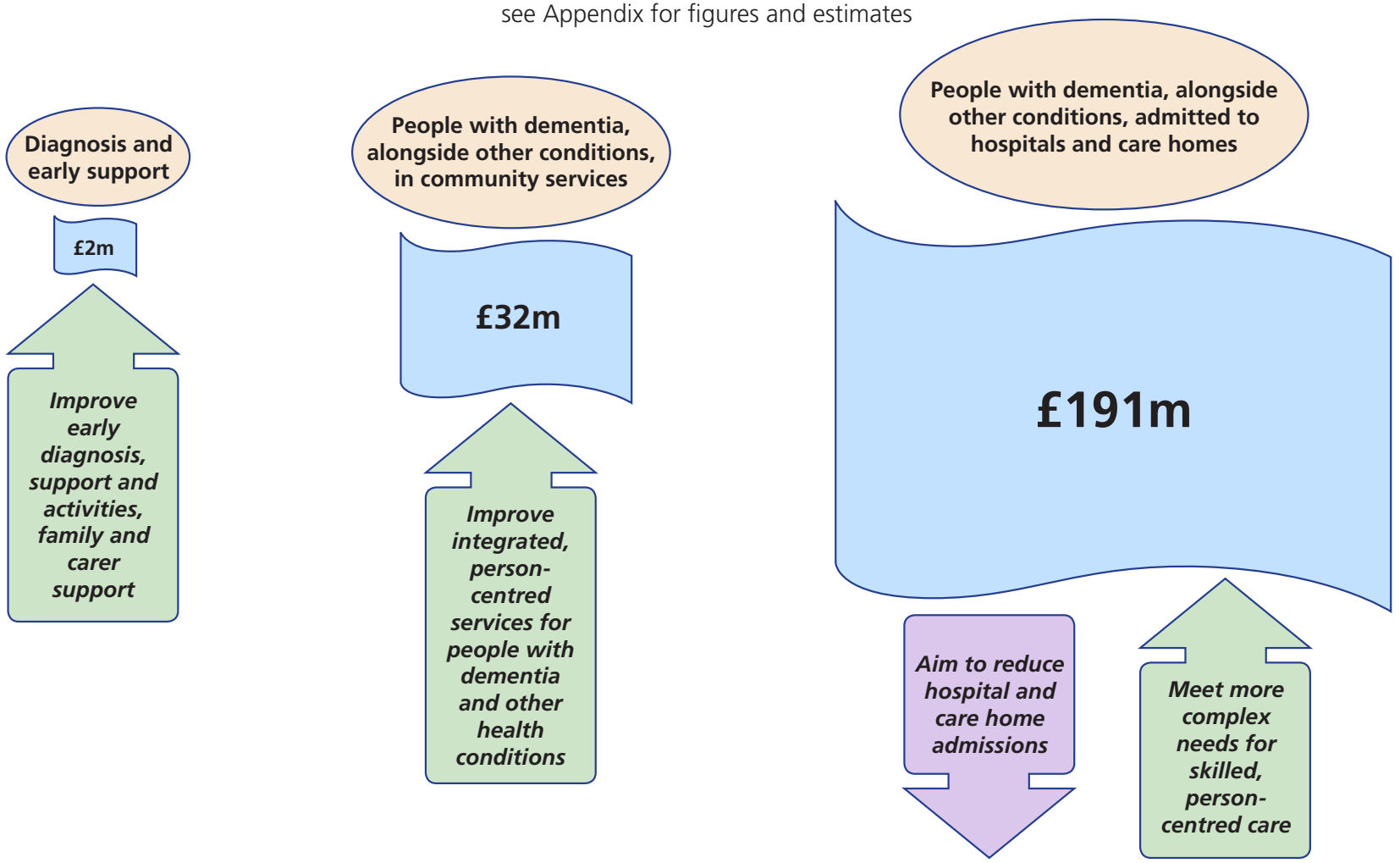
4.10 People who access services such as dementia cafés, carer support workers and dementia advisors, and other community support which includes people with dementia, can remain with these kinds of support for long periods. Therefore, the "early support" which starts after diagnosis, can provide support and a point of contact for the initial stages of the dementia journey.

4.11 Dementia is linked to high costs of health and social care. Nationally, there is evidence that people with dementia account for perhaps 25% of all hospital admission costs and 80% of older people's care home costs. This would total approximately £185m per year without including costs of care at home, specialist dementia inpatient beds, or accommodation; or the costs of unpaid caring and self-funded care which falls on families. Fig 4 summarises these estimates and compares to spending on other services. These costs are likely to increase, as the numbers of older people with dementia increase - in Leeds by approx. 2% per year. This indicates that to "do nothing" would be a very costly option.

Fig. 4:

Dementia in Leeds – estimated annual spend on selected services

see Appendix for figures and estimates



4.12 We will not reduce future costs of care by trying to tackle dementia on its own. It is important to have an integrated approach with other work going on in Leeds, to support people to live well with long-term conditions, and to reduce hospital and care home admissions. People at highest risk are likely to have other health conditions (co-morbidity) and frailty, defined as "an unstable state in which minor events – such as a urinary tract infection – can have major consequences such as delirium, falls or loss of mobility" [6] .

4.13 From April 2013 there will be an indicator shared between the NHS and adult social care outcomes frameworks. The Department of Health has funded research to inform the indicator, so the definition is not expected until 2014 at the earliest ; but it will be a measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life for people with dementia.

What we need to improve

Benefits of integrated support for the dementia journey:

- People and families / carers will not be left alone with a diagnosis of dementia, and will have a route into support as the condition develops.
- We will promote well-being and independence as much as possible, and improve quality and experience of post-diagnosis care.
- It will support compliance with NICE quality standard for dementia.
- Work collaboratively to support people with different 'co-morbid' long-term conditions, maintain well-being and reduce future costs of care.

4.14 People with dementia and families / carers, need information, advice and guidance available at any point in the dementia journey. GPs have an important role and are often the first point of contact, but often require guidance and support from specialist NHS colleagues. This supports people to manage risks and crisis points as changes in the condition occur, and thereby reduce anxieties about coping in future.

4.15 People who have both dementia and other co-morbid conditions, which together cause higher levels of need and risk, do not consistently have good care from existing services. Services which provide eg. rehabilitation and preventive services do not all have staff with dementia awareness and skills, or ready access to support from dementia specialists; but neither are physical needs met by specialist mental health services. We already have a model of "liaison psychiatry" in hospital, which means clinicians can work together to treat physical and mental health needs. Community-based services have potential to benefit from a similar model.

Priorities

- Design of early support and "self management" services to ensure that they have capacity to meet needs for people in the mild to moderate stages of dementia, and routes to access specialist help when needed.
- A consistent standard of reviewing of people diagnosed with dementia and carers.
- Staff in primary care and community health and social care to have access to specialist support, training and advice, to better meet needs related to dementia.

[6] Prof Steve Iliffe, A Quick Guide To Commissioning Dementia Care, Pulse Today (2012)

[T] See Hansard, 26th Feb 2013, column 430-431W – answer from Norman Lamb to Hazel Blears. http://www.publications.parliament.uk/pa/cm201213/cmhansrd/cm130226/text/130226w0003.htm

5 Families and carers

Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.

.....

Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia.

NICE quality standard for dementia

Overview

5.1 Carer support is addressed in national policy by Recognised, valued and supported – next steps for the carers' strategy (2010), and there are proposals to strengthen carers' entitlements to support and breaks in the White Paper Caring For Our Future (2012). Improving support for carers is essential to the well-being of carers, and people with dementia alike. The caring role is a very valuable one; at our Leeds dementia event in May 2012, a workshop on the needs of carers stated that carers should have high expectations and standards of services and support.

5.2 Caring for a person with dementia can be difficult, exhausting and frustrating, and even a few useful hints and tips can make a huge difference to the experience of caring. The experiences that families and carers find especially difficult include:

- The impact of dementia on individual and family relationships, social life and friendships
- If the person with dementia is unable to acknowledge the condition and their needs.
- Concerns about personal safety if the person is left alone.
- Lack of sleep if day-night orientation is affected.
- Frequent repetition of questions and conversations.
- If the person with dementia becomes frustrated and / or aggressive.
- Taking on financial affairs and dealing with legal arrangements.

Go with the flow - don't scold, don't contradict. Don't try and make things normal, because things may not be normal ever again.

Barbara Pointon, wife of the late Malcolm Pointon

5.3 Carers may take on the role of speaking up for the cared-for person, as mental capacity is affected by the progress of dementia. There are anecdotal examples of family carers being left out of assessments and discussions (eg. if not present at a hospital admission, or if a duty social worker is checking a referral on the telephone). The risk of omitting loved ones and carers from discussions is even greater if there is no official 'status' to a long-term relationship , e.g. for lesbian and gay older people.

5.4 Carers Leeds and the Leeds Alzheimer's Society have each recently appointed a dementia carer support worker, to strengthen our local offer of support. There are currently (March 2013) three carer support groups in Leeds for carers of people with dementia. The dementia café model in Leeds offers support to carers, who can attend alone, or with the person with dementia.

5.5 Leeds Shared Lives is a carer break service which involves a shared lives worker either coming to be with the person with dementia at home, or using the worker's own home as the base, so the carer can have a break. The carer can leave the house for a few hours, or overnight. The service is not exclusively for people with dementia, but in practice the model seems especially suited for, and is well-used by, people with dementia. The worker is selected by 'matching' for compatibility and shared interests, so the relationship can develop to feel like a natural and friendly one, and the person with dementia does not have to go into an unfamiliar environment. Leeds Shared Lives and other home-based respite provision has recently been supported through carer breaks funding via the NHS, with dedicated support to set up a direct payment arrangement to purchase the services.

5.6 Other carer break services are accessed via social care assessment including carers' assessment. Day care is valued by carers, and can offer sufficient support for a carer to remain in paid work. Short breaks, either with Shared Lives or in a care home ('respite care'), can enable a carer to go on holiday. Both these services mean that the cared-for person is away from home and from the family carer; for people with dementia especially, this requires a skilled approach to build trust and familiarity. Residential and day services in Leeds are going through a time of change, with some Council-run services having been closed, and further services having consultation about their future, at the time of writing.

5.7 The Admiral Nursing model is provided by Dementia UK, and is a service model aimed at supporting the carer to support the person with dementia. There is a national telephone helpline, (0845-257-9406; direct@dementiauk.org) but there are no Admiral Nurses in Leeds. Elsewhere in Yorkshire and the Humber, there are services in Kirklees (recently expanded to five posts), Hull, and North Lincs. The nurses are based with local services, eg. the local NHS mental health service provider, with Dementia UK providing support. It would require significant investment to create and sustain new posts in Leeds. We will listen to the views of local carers' organisations on this service model, and monitor its results in other areas.

5.8 Hospitals are expected to improve the identification and support of carers when people with dementia are admitted; there will be a financial incentive to do so from April 2013 as part of the dementia CQUIN (see section 9), which will reward hospital trusts for completing a monthly audit of carers of people with dementia to test whether they feel supported.

What we need to improve

The benefits of improving carer support and carer breaks:

- Carers are at less risk of becoming isolated and depressed.
- Carers can continue with social life, and have a life of one's own away from the caring role.
- Maintaining economic well-being, via paid work and / or benefit entitlements.
- Carers will be less stressed and better able to respond to the needs of the cared-for person.
- Services in Leeds will comply with the NICE quality standard for dementia.
- We will prevent crises and reduce costs of care.

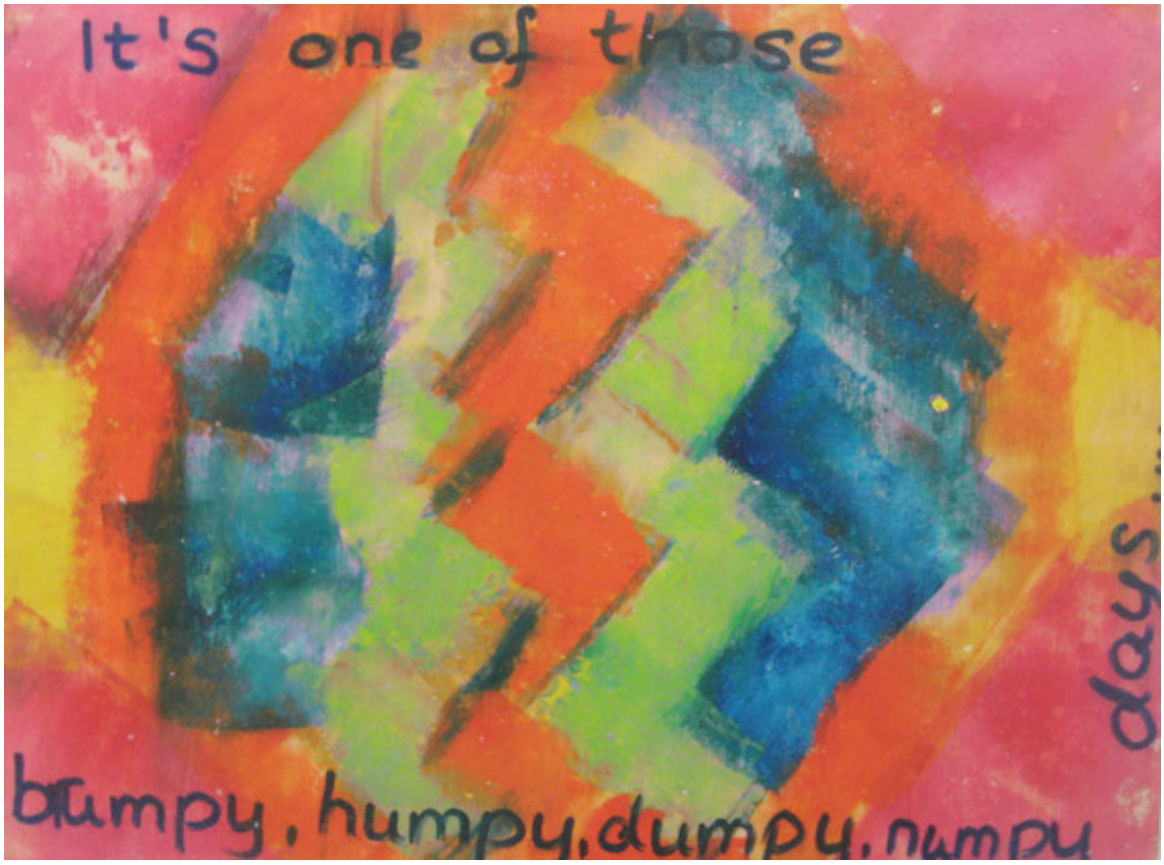
5.9 Leeds has services and groups for carer advice and support, for all carers and specifically for people with dementia. However, as with other self-management support, there is not yet a routine identification of carers and connection made to carer support. Carers comment that information provision could be improved, including information about the condition and how it progresses.

5.10 New investment has aimed to address with the waiting lists for Shared Lives and other home-based support, via the use of Direct Payments. There is a need to monitor that improvement has been achieved and is sustained.

5.11 There is reported lack of continuity in care home respite, when independent sector homes are used. This is because short respite breaks are purchased one at a time, and the availability of a bed cannot be guaranteed in the same care home. This can make it difficult for a carer to plan ahead.

Priorities

- development of self-management support and new investment (section 2), must include carer support, and improvements to information for carers.
- improve access to advice and support for carers, eg. to understand changes in a person's dementia, and develop coping strategies.
- improve the provision of carer breaks.
- the carers element of the hospital dementia CQUIN – carers feeling supported when the person cared-for is in hospital.



6 The workforce

People with dementia receive care from staff appropriately trained in dementia care.

NICE quality standard

Overview

6.1 The quality and sympathy of staff is crucial to the experiences that people with dementia have of treatment and care. The right values, attitudes, skills and knowledge are necessary to provide dignity and good outcomes from treatment and care. We need staff who understand dementia well, yet can see the person first and foremost, before the dementia.

6.2 Very simple and small changes can make a huge difference. For example, a person with dementia and sight loss might not understand that there is anything to eat on a pale-coloured plate with pale-coloured food; or be confident that an opaque plastic beaker contains anything they'd like to drink. People with even a mild dementia can become confused when unwell and admitted to an unfamiliar hospital setting. The skills and knowledge to understand people and how to respond can come from training courses, and from working alongside colleagues.

Our staff attended 'Food for Life' training and got the idea of using coloured plates for people with dementia, so the food on the plate is more visible than using a plain white or patterned plate. We tried this at the care home with two residents with dementia, and monitored weights for one month. They ate more and gained weight. For one of the gentlemen his nutritional intake improve so much over three months that his iron / vitamin medication was stopped.

Care home manager in Leeds, May 2012

6.3 The National Clinical Director for Dementia, Professor Alastair Burns, has suggested that health and care services need staff who are "100% dementia aware, 50% dementia trained, and 10% dementia specialist". This is a rule of thumb and will vary according to the nature of the service, but is a useful guide. A hospital ward or a care home must have all clinical and care staff, whether professionally qualified or not, competent to provide person-centred care. New ways of working, for example in integrated health and social care teams, will require new skills for working with people with dementia.

6.4 The NHS Operating Framework 2012-13 requires NHS providers to report on progress to the NICE dementia quality standard in their annual quality accounts. Commissioners are expected to ensure this is specified. Within the quality standard, the workforce statement is, arguably, the single one that all providers have in common, and within their direct control. Training of staff and leadership of ward teams is an element of the dementia CQUIN for NHS hospital trusts (see section 9) from April 2013. This means that there is a financial incentive attached to ensuring that there is clinical leadership and delivery of a training programme.

6.5 Staff and volunteers involved in well-being activities and services need dementia awareness and training. For example, ways of including people with dementia in mainstream activities; reminiscence work that helps a person feel validated rather than out-of-touch; supporting people to feel settled and join in. Training courses for volunteers and staff in voluntary and community groups, is being offered in January and February 2013, covering dementia awareness; training paid co-ordinators to train volunteers; inclusion in activities; and reminiscence work.

6.6 Dementia Care Mapping is a method for training staff to be person-centred in all interactions with people with dementia, and for managers to assess how well staff are relating to people with dementia. Leeds City Council has funded training for managers in its own services, and some independent sector care homes, and is bringing trained 'mappers' together to support each others' work. The Mount inpatient unit (run by LYPFT) has invested in training its staff in dementia care mapping.

6.7 Carers must, at times, be understood as part of the workforce. A carer is doing an important job, without ever having wanted or applied for it, and without any training. Carers and people with dementia can also contribute to paid staff training, to improve awareness and understanding.

What we need to improve

The benefits of improving workforce development are:

- People with dementia can be assured that staff have the right skills and knowledge.
- Carers are treated as expert partners.
- Services in Leeds will comply with the NICE quality standard.

6.8 A systematic approach is needed to ensure that Leeds health and social care providers progress to compliance with the workforce statement in the NICE quality standard. This is a major challenge across our NHS Trusts and over 100 private sector providers of domiciliary care and care homes.

6.9 There is a wide range of training available, including e-learning options for dementia awareness, but a lack of definition of what is a satisfactory standard, or how effectiveness is measured.

6.10 Dementia is usually experienced alongside other health conditions and disabilities ("co-morbidity") as described in section 4 above. The impact of this on care services, and the training needs of the workforce, is emphasised in the report The State of Health Care and Adult Social Care in England in 2011-12 (Care Quality Commission, 2013):

Overall CQC is finding that the increasing complexity of conditions and greater co-morbidities experienced by people are impacting on the ability of care providers to deliver person-centred care that meets individuals' needs. It is also seeing increasing pressures on staff, both in terms of the skills required to care for people with more complex conditions and in terms of staff numbers.

6.11 The workforce in community health and social work, including the integrated health and social care teams in Leeds, are responsible for care planning and co-ordination with people, families, carers and providers. There are skills needed to work in new ways to promote well-being and avoid admissions to hospitals and care homes.

Priorities

- Ensure all local NHS providers report on compliance with NICE quality standard, with high priority for workforce statement.
- Set and monitor workforce standards for social care providers; already included in care homes quality framework.
- Ensure Leeds Teaching Hospitals Trust plans achieve the workforce element of the dementia CQUIN.
- Consider local CQUIN incentives for other local NHS Trusts' workforce development.
- Run training for voluntary and community groups, and evaluate.

7 Emotional, psychological and physical well-being

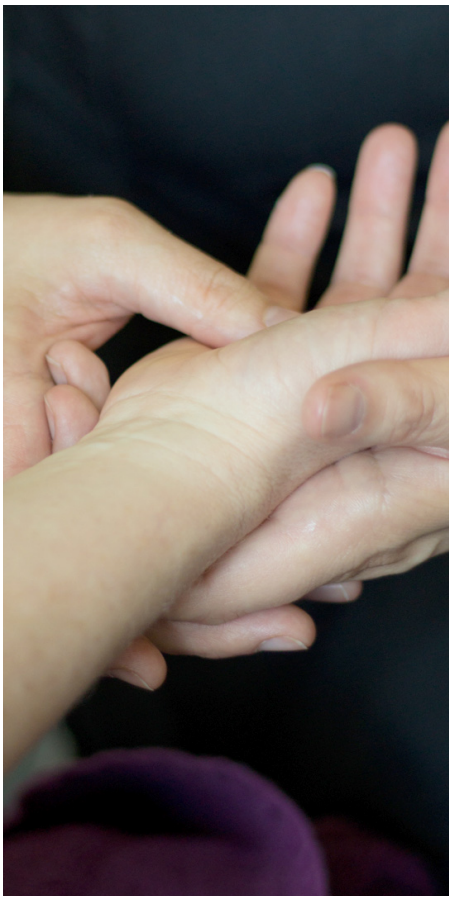
….the principles of person-centred care underpin good practice in the field of dementia care:

- the human value of people with dementia, regardless of age or cognitive impairment, and those who care for them
- the individuality of people with dementia, with their unique personality and life experiences among the influences on their response to the dementia
- the importance of the perspective of the person with dementia
- the importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being.

NICE Clinical Guideline 42 – Supporting People with dementia and their carers in health and social care

Overview

7.1 Promoting well-being starts at the very beginning of the dementia journey. The risks to well-being are significant even for a person with mild dementia, and increase as the condition progresses. It can be especially harmful if every aspect of a person's difficulties is attributed to "dementia" as an irreversible and untreatable cause. People with dementia, as much or more than anyone else, suffer pain, boredom or loneliness; and struggle more to put it into words, or to do something about it. But the solution is nevertheless pain relief, meaningful activity, or company. The late Tom Kitwood at Bradford University led the way in promoting person-centred care, with psychological and social approaches to understanding and meeting needs.



7.2 Person-centred care includes:

- ✓ Meaningful activity
- ✓ Social engagement
- ✓ Access to health and well-being services

and this applies at all stages of the "dementia journey".

7.3 The "behavioural and psychological symptoms of dementia" (BPSD) is a term used to describe eg. agitation and aggression, but it is important not to over-medicalise this concept:
These symptoms can develop as part of the dementia, or they may be caused by a general health problem, for example, if the person is in pain or discomfort due to hunger, thirst or an infection. Symptoms can also be caused by problems related to the care the person is receiving, or their environment or social interactions. It is therefore very important to treat general health problems and pain and monitor changes in the person's living environment.

Alzheimer's Society website

7.4 The Right Prescription is an NHS "Call to action" (2011) to end the inappropriate prescribing of anti-psychotic medication for people with dementia. This is supported by a target to reduce prescribing of this type of medication by two-thirds for people with dementia. In Leeds, a series of audits have prompted GP practices and NHS Trusts to act to reduce prescribing according to clinical guideline, and measure whether this has been achieved. These medications can cause side effects such as increased risk of falls and stroke. The use of anti-psychotic medication in dementia remains part of the Clinical Commissioning Groups Outcome Indicator Set from April 2013.

7.5 There is evidence from projects that engage people in creative activities, that people can appear happier, talk more, and show less frustration and aggression. The inpatient wards at The Mount have run projects with The Wellbeing Centre, involving hand massage, and Artlink West Yorkshire, involving reading and creative art. If we are lucky enough to be healthy, we might see such things as 'add-ons' to services; but the less well one becomes, it may be that creative approaches and opportunities become essential for well-being.

I enjoyed having contact with my husband who usually struggles to speak to me

Carer, trained to give a simple hand massage, Leeds

She used to sit in the lounge all scrunched up and tense, leaning forward in her chair, ready to throw her juice at the next passerby. The staff said, 'Don't sit with her – she'll probably try to hit you'. So I sat down a safe distance away and said, 'I'm just going to try reading this poem. If you don't like it that's fine, but let's see what you think of it.' I read the poem through. She relaxed back in her chair, went very quiet, and at the end she said, straight away, 'read another'."

The Reader Organisation, Liverpool (from The Guardian, 5th October 2010)

By the time Barbara brought Malcolm home in 2000 he was barely speaking. Pointing to an oil landscape he painted on the wall she says: "There was a wonderful moment when he saw that painting, smiled his first smile for a long time and said 'Home'. There was a tremendous feeling of release and relief."

Interview with Barbara Pointon (from The Guardian, 12th December 2007)

7.6 Person-centred care concerns the whole of a person's daily experience. A short activities session, however enjoyable, may still leave many unoccupied hours in a day. Involvement in daily routines, and activities based on what a person can do are often beneficial. The approach of Dementia Care Mapping concerns the quality of daily interactions with others, and has been developed for care home settings and, more recently, domiciliary care / supported living.

7.7 People with dementia may have poor access to 'mainstream' health care, either because clinicians need specific support to work with the person, or because of misunderstandings and negative attitudes. Examples of important services would be testing and correction for sight and hearing loss; rehabilitation services; and psychological therapies for depression, for both people with dementia and carers.

What we need to improve

The benefits of improving well-being people with dementia include:

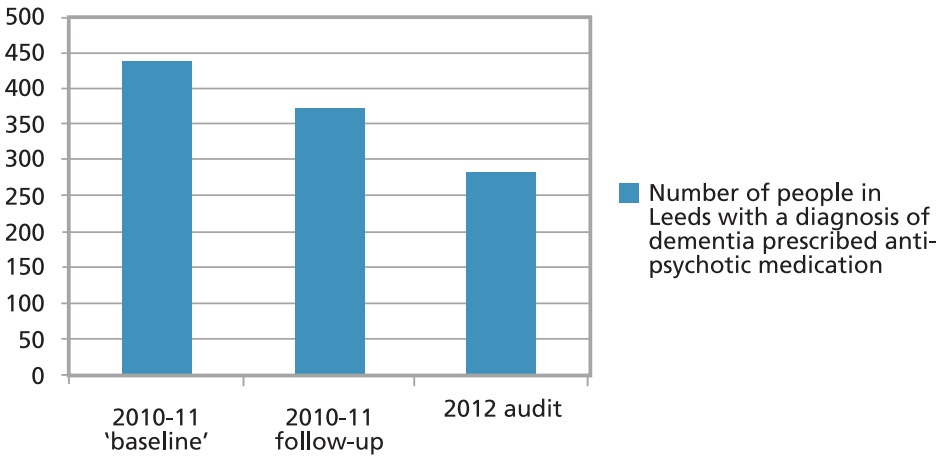
- better quality of life and sense of dignity;
- delaying the onset of care needs, reducing hospital admissions;
- reduced inappropriate use of anti-psychotic medication and side-effects;

More advice on how to reduce the decline – activities to exercise the mind, ways that the person is encouraged to do things for themselves, rather than just sat staring into space all day.

Son of an older person living with dementia, Leeds

7.8 A series of local audits has shown that anti-psychotic prescribing for people diagnosed with dementia has decreased over the past two years (Fig 5). This shows significant decreases have been achieved, and the 2012 audit requires each GP practice to plan actions to review patients. A follow-up audit has been carried out and results will be analysed in spring 2013.

Fig 5. Reduction in anti-psychotic prescribing in dementia.



NB:
- 2012 figure includes people aged 65+ on a low-dose anti-psychotic, who have not had a diagnosis of dementia recorded.
The Right Prescription estimated that 20% of people with dementia are prescribed anti-psychotics, which would equate to 800 people with a dementia diagnosis in Leeds.

7.9 To ensure good practice is embedded in Leeds, a task group has been established by the Leeds Dementia Board and Leeds Area Prescribing Committee, to produce a local guideline to include:
- local information about approaches such as improving person-centred care and "watchful waiting". Local audit showed evidence in only 43% of cases that such approaches had been tried before prescribing.
- improving clarity and handover at transitions of care, eg. between NHS Trusts and GPs, and geographical moves.

7.10 There is wide variation in care practice, which could be improved by support for families and carers, and training and development for the workforce. Staff may lack the time, skills and / or confidence, to improve standards of care. Enabling staff to spend time in positive occupation and stimulation, and responding to signs of loneliness and emotional need, could reduce the time spent reacting to agitation and aggression.

7.11 Opportunities for occupation and creative activity are limited. Recent small grants have promoted more opportunities run by community groups, including creative arts, singing and supported outings.

Priorities

- Task group to complete a Leeds guideline for management of "behavioural and psychological symptoms in dementia", including anti-psychotic prescribing.
- Workforce initiatives (section 6) must go beyond dementia awareness, to include competence to provide for emotional and psychological well-being.
- Promote and evaluate therapeutic and creative activities in community and care settings, including supporting applications for external funding.

8 Rights, risks, choice and control

We all face risk in our everyday lives and regularly make judgements, sometimes unconsciously, about risks and benefits for everyday actions. It is a challenge to tread the line between being overprotective (in an attempt to eliminate risk altogether) while respecting individual freedoms.

Alastair Burns, National Clinical Director for Dementia
Foreword to *Nothing Ventured, Nothing Gained – risk guidance for people with dementia* (2010)

Overview

8.1 People with dementia are at risk of losing self-determination and a sense of control over one's own life as dementia progressively affects the ability to understand information and make decisions independently. There is, however, a range of legislation and guidance that supports people's rights, and support available to manage risks. This section considers:

- mental capacity legislation.
- advocacy.
- support for personal safety.
- self-directed support in social care and health care.
- safeguarding procedures.

8.2 The principles of the Mental Capacity Act (2005) are:

- Every adult has the right to make his or her own decisions and must be assumed to have capacity to make them unless it is proved otherwise.
- A person must be given all practicable help before anyone treats them as not being able to make their own decisions.
- Just because an individual makes what might be seen as an unwise decision, they should not be treated as lacking capacity to make that decision.
- Anything done or any decision made on behalf of a person who lacks capacity must be done in their best interests.
- Anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms.

Dementia often affects the ability to retain and analyse information, and understand the consequences of a decision; but the legal framework does not permit any kind of "blanket" approach to dementia and decision-making. It is wrong to assume that a diagnosis of dementia makes a person incompetent to make a decision. Furthermore, it is wrong to generalise when we might be competent to make some decisions, but less competent to make others.

8.3 People with dementia are among those most at risk of losing one's autonomy, and may require advocacy, defined by Action for Advocacy as *taking action to help people say what they want, secure their rights, represent their interests and obtain services they need*. There are different types of advocacy, all of which are important for people with dementia. "Statutory advocacy" describes specific services

which must be provided, including Independent Mental Health Advocate (IMHA) and Independent Mental Capacity Advocacy (IMCA). "General advocacy" describes a broader advocacy service, which is not directly specified by name in any legislation, but at the very least contributes to fulfilling equality duties regarding access to service provision.

8.4 From the beginning of the dementia journey, we are faced with a confusing and worrying situation, and difficult decisions to weigh up, which are very difficult to do alone. Therefore advocacy can be very helpful to support 'self-management' of dementia. Further on, the risks associated with dementia can lead to disagreements between the person and concerned family members, and indeed professionals; again advocacy can play a valuable role. In the later stages of dementia, people might have severe difficulties understanding information and expressing oneself, yet there are important decisions to be made about safety, treatment and care. This means that"uninstructed" advocacy may be important to make certain that decisions are taken with due consideration for their unique preferences and perspectives (Action for Advocacy).

8.5 The early stages of dementia can be an opportunity to make a Lasting Power Of Attorney, which can be drawn up to cover both financial affairs and / or health and welfare. It is a good idea for everyone to make a Lasting Power of Attorney (LPA), it can be done alongside making a will, and like a will, it can reduce complications and distress at difficult times for one's family. To make an LPA requires the capacity to make the necessary decisions, but it is activated when the capacity for relevant decisions is lost.

8.6 Staying safe and secure at home can be an early concern for people with dementia, and often a concern for families which the person with dementia might be less aware of. Anecdotally, it may often be the first thing that causes family members to think that a move to supported accommodation or residential care might be needed. However, there is a lot of help available to improve home safety. West Yorkshire Fire and Rescue Service offer fire safety checks for vulnerable people. West Yorkshire Trading Standards have recently obtained Lottery funding for work in Leeds and Bradford to prevent 'scams' and doorstep crime; they also work with local Neighbourhood Watch schemes eg. on "No Cold Calling" zones, for example in areas of Otley. The Leeds Telecare service provides devices which can eg. detect gas if a hob is left on and unlit, or whether a door has been opened in the middle of the night. Leeds Care and Repair can fit equipment and minor adaptations to reduce risk of falls, or improve home security.

8.7 Reablement, skills support and a specialist home care service are provided by the local authority's home care (domiciliary care) service. The majority of home care for older people, including older people with dementia, is from independent sector home care providers. The local authority purchases care only from providers which qualify via its "provider framework". When this is next tendered out, will be an opportunity to review and set standards for care of people with dementia.

8.8 Self-directed support is an entitlement for people who have needs and risks at which are eligible for social care services. This represents a real opportunity for people with dementia and carers, because 'traditional' care packages (home care, day care, residential 'respite' stays) do not always meet the needs related to dementia. For example, a person with dementia:

- may need help at unpredictable times, or someone on hand throughout the day, rather than the same tasks at regular times;
- may not trust others to help with personal care;
- may become agitated on a long journey to a day centre.

A Direct Payment or other form of personal budget can be used to design one's own package of care, and develop flexible arrangements with a personal assistant or care provider. Support is provided by the Leeds Centre for Integrated Living (CIL) through their ASIST service to eg. recruit personal assistants,

and set up managed bank accounts. People with dementia have used this scheme to develop self-directed support, though numbers are small at the moment.

8.9 Extra-care housing is a service model which combines one's own tenure of a flat, with 24/7 availability of care and support. It can offer an alternative to residential care; the opportunity for couples to stay together when one person has care needs; an enabling environment which can reduce care needs; and improved access to activities and stimulation. There is limited provision for people with dementia in two of the seven schemes in which Leeds City Council has been a partner. Future development is in the planning stages (at time of writing) and are an opportunity to ensure that people with dementia and spouses / partners are included in new developments, and the at new schemes can meet needs as dementia progresses.

8.10 People with dementia , along with other vulnerable adults, are covered by the arrangements under the Leeds Safeguarding Adults Partnership, for protection from abuse and neglect. All service providers must follow the agreed policy and procedures when there are safeguarding concerns. Dementia generally makes people more vulnerable and less able to speak out, therefore safeguarding can be a crucial service.

What we need to improve

The benefits of improving practice to support people's rights are:

- People with dementia do not experience violations of human rights and other legal rights.
- People with dementia feel valued.
- Treatment and care will work better, from being suited to individual needs.

8.11 The understanding of clinicians and care staff about people's rights, the mental capacity framework and advocacy provision.

8.12 Awareness and co-ordination of the support available to stay safe and secure.

8.13 More people with dementia to benefit from the opportunity for self-directed care, and the support to manage an individual budget; eg. to purchase home-based carer breaks, or a personal assistant to assist the person both at home and to go out.

8.14 There is local provision of extra-care housing for people with dementia, but a relatively small capacity.

8.15 Better understanding of safeguarding concerns and service complaints involving people with dementia.

Priorities

- Capacity for dementia advocacy services to increase provision, and promote awareness and uptake of advocacy, for people with dementia and carers.
- Information about practical help to be safe and secure, to be included in the post-diagnosis provision of information.
- Promote good examples of self-directed support and increase the numbers of people with dementia who benefit from it.
- Extra-care housing developments in Leeds to ensure suitability people with dementia, with the capacity to meet people's needs and prevent further moves to residential care.
- Understand what safeguarding and complaints information can tell us about dementia care standards and how to improve services.

9 The Right Care – people with dementia in hospital

> Good care can make an incredible difference. On her first visit to hospital my mother received brilliant care. The kindness and skill of the hospital staff reassured and comforted her. However, when she was admitted for the second time no one even realised she had dementia. The doctor didn't have time to find her notes and was under the impression my mother had to go home to look after my father despite the fact that my father has been dead for five years.
>
> *Angela Rippon, foreword to Counting the Cost…, Alzheimer's Society (2009)*

Overview

9.1 This section refers to people admitted to "general" or "acute" hospital, rather than to specialist inpatient units for people with dementia. This service in Leeds is provided by the Leeds Teaching Hospitals Trust (LTHT) at Leeds General Infirmary, St James Hospital, and by the smaller hospitals (which now have mainly eg. outpatient services, day surgery). Dementia is important because the condition, and sometimes lack of support with the condition, increases the risks of physical health problems developing and of hospital admissions. At any one time, it is estimated that 25% of hospital beds are occupied by people with dementia. This estimate has support from research evidence and is commonly quoted in national policy.

9.2 It is likely that this is caused by not only the numbers of people with dementia admitted to hospital; but also to the lengths of stay once admitted. In Leeds, there were developments in liaison psychiatry and intermediate care from 2006-10, which led to:

- improved detection of dementia (up 57% over the 4 years)
- reduced lengths of stay for people with dementia (down 30% over the 4 years).

Therefore Leeds hospitals may have fewer than the national average inpatients with dementia. Up-to-date data is required to verify this.

9.3 Acute hospitals have a financial incentive to improve the detection of dementia and provision of treatment and care. This is through the NHS Commissioning for Quality and Innovation scheme (CQUIN). The dementia CQUIN from April 2012 applies to people aged 75+, admitted 'unplanned' for more than 72 hours, and covers the process of "Find – Assess and Investigate – Refer" (FAIR) for detection of dementia and increase in diagnosis. The CQUIN from April 2013 will cover this FAIR process, plus staff training and leadership, and carer support.

9.4 Leeds Teaching Hospitals Trust has incorporated the FAIR process in its 'pathways' from Accident and Emergency admission through inpatient care to discharge. Each stage of the screening, assessment and referral process is built into existing documentation, and staff training has been rolled out across all departments. Generally, the referral route is to the GP, using the electronic discharge advice note (eDAN), recommending referral to memory clinic. The Trust is now meeting the 90% target for the CQUIN. Initial figures suggest this is producing 70 - 90 recommendations to GPs each month, to either refer to memory services or to assess further.

9.5 The Right Care is an NHS Call To Action to improve the experience and the results for people with dementia admitted to hospital.

- The environment in which care is given.
- The knowledge, skills and attitudes of the workforce
- The ability to identify and assess cognitive impairment
- The ability to support people with dementia to be discharged back home
- The use of a person-centred care plan which involves families and carers

9.6 The Care Quality Commission (CQC) states in its annual publication The State of Health and Adult Social Care in England in 2011-12, that in the coming year it will carry out a follow-up inspection programme looking at issues of dignity and nutrition in 50 NHS hospitals; and review information and data on dementia care during admissions to hospital.

What we need to improve

The benefits of improving hospital care for people with dementia will be:

- Better experience and well-being for people with dementia and carers".
- All hospital staff trained, more able to meet needs of people with dementia, and to feel satisfied with the care they're giving.

9.7 The Leeds Teaching Hospitals Trust long-term quality plan refers to the dementia CQUIN, but not to the broader aspects of care quality and people's experiences in hospital. The publication of The Right Care and ensuring compliance with NICE quality standard, are opportunities to promote a broader perspective on quality of dementia care. LTHT has designed and is implementing a training programme for all its staff, which has identified the different levels of traning required for the different staff roles within the hospitals.

Priorities

- Implement the *Call To Action – The Right Care* within Leeds Teaching Hospitals Trust (LTHT).
- Develop Dementia-friendly environments on wards used by older adults; this will require capital investment
- Formalise a care pathway to detect and manage dementia, delirium and depression.
- Ensure clinical leadership capacity to implement change, eg. through a lead nurse role.
- Implement 'Know Who I Am' document and ensure it is used and referred to, to plan and deliver high quality dementia care in hospital.
- To ensure compliance with NICE quality standard for dementia, in particular workforce statement (cf. section 6 of this document).

10 Specialist NHS services

A comprehensive dementia commissioning programme includes: .....specialist mental health care services for patients with dementia who present with behaviours that challenge, patients whose dementia is complicated by comorbid functional mental health problems, and those with complex diagnoses....
This service will have a strong community focus, but will have access to a limited number of inpatient beds.

Joint Commissioning Panel for Mental Health – Guidance for commissioners of dementia services

Overview

10.1 The Leeds and York Partnership Foundation Trust (LYPFT) provides a range of services, some of which are referred to elsewhere in this document:

- Memory service: This is a dementia-specific specialist service, and has been referred to in section 2 and elsewhere.
- Liaison psychiatry: Supports patients and clinicians in acute hospital settings, when there are both physical and mental health needs, and is referred to in section 9.
- Care homes liaison service: Supports people and staff teams to meet mental health needs, and is referred to in section 11.

This section covers the other specialist mental health services which people with dementia use. People living near the Leeds local authority boundary may be referred to neighbouring NHS services.

10.2 LYPFT has introduced important changes as part of its internal "transformation" programme, including:

- a Single Point of Access, so referrals come in on a single number, and are directed to the appropriate team or person.
- community teams which work with all adults, to replace separate services for "working age" and older adults.

10.3 There are three community-based specialist services for adults with mental health needs. Community Mental Health Teams are multidisciplinary teams which support people judged to be at highest risk / most complex needs, using the Care Programme Approach (CPA). Intensive Community Services (ICS) offer home-based interventions, including hospital discharge support; and a Crisis Assessment Service responds to urgent need.

10.4 LYPFT provides a specialist Younger People With Dementia Team, working with people whose onset of dementia is, generally, under the age of 65. There are specific needs such as parenting, employment, relative physical fitness, that benefit from a specialist multidisciplinary service, as recommended in the NICE clinical guideline (para. 1.1.2).

10.5 There is a dementia-specific inpatient service at The Mount, with the role to care for and treat people when the person is experiencing and presenting with severe and complex needs, and cannot be supported for safe assessment and treated in other settings. There are now (March 2013) 40 beds (20 in an all-male ward, 20 in an all- female ward), following the change of use of Asket Croft during

2012. This provision includes people who have been detained compulsorily under mental health legislation. The service is developing its environment, including a new garden area opened in 2012. The service has invested in 20 places for training in dementia care mapping (DCM) at Bradford University, and has two clinicians trained at practice development level DCM. This method aims to evaluate person-centred care, observing interactions with staff from the perspective of the person with dementia.

What we need to improve

Benefits of improving specialist mental health services include:

- Better integrated care for people with both physical and mental health needs.
- Better access to community support for people at home, or leaving hospital.

10.6 Better integrated working between specialist services and other community health and social care services (see section 4).

10.7 The new service configuration has meant that staff without experience of older people's mental health needs, are providing specialist mental health services for people with dementia. Therefore there are staff training needs within specialist community services.

10.8 Hospital-based clinicians have stated that the ICS team has not been able to offer the same levels of service for people leaving hospital, as the former Mental Health Intermediate Care Teams was able to. LYPFT review of the new services has acknowledged the need to ensure older people's access to services and increase the use of home-based treatment.

10.9 The service at The Mount is planning further environmental improvements, to develop use of the new garden area, promote better orientation and confidence around the ward areas, and improvements to bedrooms to promote good sleeping patterns.

Priorities

- Improving the skills of workforce to meet needs related to dementia, to ensure all-adult teams are compliant with NICE dementia quality standard.
- LYPFT recommendations following service transfomation – to improve the capacity of the all-adult teams to meet needs related to dementia, especially in people's own homes.
- Environmental improvements at The Mount, including bedrooms and ward reception areas. These will require capital investment.
- Better local understanding of specialist service provision via the dementia needs assessment.

11 Living well in care homes

> It can be difficult for staff to know what is important for individual residents with dementia…. In the day-to-day bustle of 'getting on with the job', there is always a tendency for staff to resort to what they think a resident wants.
>
> *Put yourself in my place – Cantley and Wilson / Joseph Rowntree Foundation (2002)*

Overview

11.1 It is estimated that 80% of older people living in care homes have dementia, with the proportion ranging from 50% in "mainstream" residential homes, to 100% in some specialist homes. This estimate comes from the Alzheimer's Society's *Low Expectations* report (2013), and revises the previous estimate of 65% (from their *Dementia UK* report, 2007). Although much of this strategy is concerned with promoting well-being and independence, and avoiding admissions, nevertheless the provision of good care in care homes is very important for people living with dementia and for families. Other sections of this strategy have specific relevance to care homes: workforce; rights, risks, choice and control; and emotional and psychological well-being.

11.2 Leeds City Council has introduced a new 'quality framework' to set minimum contractual standards for local homes, and offer a financial incentive for homes to invest in and demonstrate high standards, including working with people with dementia.

11.3 Leeds and York Partnership Foundation Trust (LYPFT) provides a care homes liaison service, which responds to requests from care homes and GPs to work with residents and develop care plans. A new service specification is being developed which aims to raise the standards of dementia care in the care home sector, and promote a skilled and confident approach which reduces the need for crisis intervention.

11.4 NHS support to care homes covers a wide range of conditions and initiatives in addition to and linked to dementia - such as end-of- life care and falls prevention. Leeds South and East Clinical Commissioning Group are introducing a "local enhanced service" for their GPs to provide an increased level of service for people in care homes.

11.5 Many local care home providers belong to the Leeds Care Association, which is represented on Leeds Dementia Board, as well as being a training provider linked to Skills for Care.

What we need to improve

The benefits of improving quality of care in, and support to, care homes, are:

- Improved well-being for people living in care homes;
- Families and carers will feel less anxious;
- Staff teams are more confident to meet needs and prevent crises occurring;
- Reduced admissions from care homes to hospitals.

11.6 There is wide variation in care home standards regarding quality of care and quality of life. Improving the quality of care homes means improving dementia care, across the sector and not just for specialist homes.

11.7 This is a real challenge for the care home sector, with the number of older people in care homes reducing as more people are supported to stay at home. As this trend continues, people living in care homes are more likely to be those with more complex needs. The *Low Expectations* report (see above) emphasises the constraints on public funding, the need to improve information for families, aspire to high standards, improve support from NHS services, reduce moves between care homes.

Priorities

- New service specification for care homes liaison (LYPFT).
- An integrated approach to care home support from health services.
- Developing the workforce (cf. section 6) to improve care standards.

12 End of life care

There are three ways in which people with dementia die:

- People who die from the complications arising from end-stage dementia
- People who may be in the early stages of dementia who die from another illness, e.g. cancer
- People who die with a mix of mental and physical problems. Dementia may not be the main cause of death but it interacts with other conditions.

Alzheimer's Society, position statement on palliative care, citing Cox and Cook, 2002

12.1 Dying with or from dementia is the experience of an estimated 1,500 people each year in Leeds. In common with palliative care for any terminal or long-term illness, the experience of 'a good death' is important for the person and for family and friends. The stigma attached both to death and to dementia, can make this difficult to discuss and therefore to achieve.

12.2 My life until the end – Dying well with dementia is an Alzheimer's Society report exploring the experiences of families, the importance of a "good death", and what this means with dementia.

It makes recommendations including:

- public awareness, promoting honest conversations and reducing stigma.
- care planning and decision-making, including planning well in advance.
- dignity, based on understanding and person-centred care.
- pain - the skills to both diagnose and relieve pain for people with dementia.
- decisions about withdrawing and withholding treatment, and the importance of specialist palliative care services.
- Emotional and spiritual concerns.
- Place of death.

12.3 People with dementia, especially at the late stages, might struggle to communicate feelings and symptoms, or to understand and co-operate with e.g. the usual methods for administration of medication.

12.4 The complexity of needs in the late stages of the condition, means that the majority of people die in a care home or in hospital. This may be the choice of the person and family, and is entirely appropriate when a care home has been the person's home for some time. However, unplanned admissions very near to end of life can be upsetting, and can often be prevented by community services.

12.5 This is best achieved where there is a shared understanding that the person is approaching end-of-life, and there has been the opportunity to agree with the patient (if possible) and family that the focus of care should be aimed around good symptom management and maintaining quality of life and dignity, not attempts at prolonging life at all costs. This information needs to be available , eg. via GP palliative care register, to all professionals involved so mechanisms can be put in place, including the availability of medications, to ensure patients can be cared for and die in the usual place of residence where possible.

12.6 Specialist palliative care services in Leeds have taken the lead to improve support for people with dementia near to end of life. In practice, this includes encouragement to consider Advance Care Planning at an early stage and the production of information for clinicians on the end of life signs ('prognostic indicators') for dementia; and how to recognise and treat end of life symptoms such as pain and nausea.

12.7 Bereavement for families and friends may be complex and difficult, and we need to understand local needs and how well services are supporting people. Support might come from families, friends or from providers who have been involved with the person during the dementia journey. The better we do at including people with dementia and families in social and community life during the dementia journey, the less isolated people will be in grief.

What we need to improve

The benefits of improving end-of-life care will be the opportunity for people with dementia and families to plan and prepare, more people experiencing a comfortable and dignified death, and avoiding preventable and undesirable moves near to end of life.

12.8 Very few people are supported to plan and prepare for the end of life when dementia is at a relatively early stage. It is not easy to raise the subject, especially when the emphasis is on living well with dementia and being positive about the condition.

12.9 There appear to be unnecessary admissions to hospital near to end of life. Hospitals can provide very good end-of-life care, but the Alzheimer's Society report (above) includes examples where people have died on noisy wards and staff did not, or were not able to, provide for a good death. A recent local audit of hospital admissions from care homes, from people who died in hospital in the end-stages of long-term conditions, showed poor evidence of advance care planning, which may have helped the person to remain at the care home.

Priorities

- Complete and introduce clinical guideline to detect and manage pain and other symptoms in later stage dementia.
- To ensure dementia is included in local plans to improve end of life care and planning.
- Advance care planning in the care home sector, and avoiding unnecessary admissions.
- Improve provision of advocacy to support care planning decisions.

Some people who have lost loved ones with dementia find that they grieve so much during the course of the illness that they have no strong feelings left when the person dies. Others experience a range of overwhelming reactions at different times. These may include:

- *numbness, as though their feelings are frozen*
- *inability to accept the situation*
- *shock and pain, even if the death has been expected for a long time*
- *relief, both for the person with dementia and themselves*
- *anger and resentment about what has happened*
- *guilt over an incident that happened in the past*
- *sadness*
- *feelings of isolation*
- *a feeling of lack of purpose.*

It can take a long time to come to terms with the person's death. Those who have been full-time carers for a long time will be left with a huge void when this role ends.

Alzheimer's Society Factsheet – Grief and bereavement

Appendix -

Spending on selected services for people with dementia – detail

People with dementia, alongside other health conditions, in hospitals and care homes

- People with dementia are an estimated 25% of hospital inpatients (Alzheimer's Society Counting The Cost report cites evidence for this figure). 25% of the local annual NHS spend on Leeds hospital admissions is **£120m**.
- People with dementia make up 80% of people in care homes. (Alzheimer's Society Low Expectations report cites evidence for this figure). 80% of Leeds City Council annual spend on care home admissions is **£65m**.
- Specialist inpatient beds for people with dementia – this service is allocated **£6m** of the overall contract funding for Leeds and York Partnership Foundation Trust.

Total estimate £191m

People with dementia in community services

- Leeds City Council spent £28.2m on older people's home care services in 2011-12. A study by the Public Social Services Research Unit (PSSRU) Community Support Services For People with Dementia (Challen et al 2010) found that 32% of people using their sample of services, had dementia www.pssru.ac.uk/pdf/MCpdfs/CSSr.pdf. There was no evidence comparing amounts or costs of care, so estimate assumes that dementia does not affect the average care package. 32% of £28.2m gives estimated **£9m**.
- Leeds Community Health received £127m funding for services to patients in 2011-12. NHS data for community nursing referrals suggests that two-thirds of referrals are for people aged 65+[1]. A conservative estimate has been made from this, that older people account for 50% of expenditure. It has been assumed that the profile of older people using the service is similar to home care, ie.32% have dementia. 32% of 50% of £127m gives an estimate of **£20m**.
- Leeds and York Partnership Foundation Trust contract for 2012-13 gave allocations of contract funding for older people's services, prior to the creation of all-adult teams. The total allocation for Older People's Community Mental Health Teams and Mental Health Intermediate Care was £5.2m. It has been assumed that people with dementia were 50-60% of caseloads. Estimate of **£3m**.

Total estimate £32m

Diagnosis and early support

- Spending on LYPFT memory services allocated from LYPFT contract funding 2012-13 was £1.3m.
- Total dementia advisor and carer support roles, dementia cafes, activities, and peer support: c. £600K.

Totals approx. £2m pa.

NB: *This is not a comprehensive 'map' of spending, but is intended to give a picture of the overall balance of expenditure.*

[1] http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Statistics/StatisticalWorkAreas/Statisticalhealthcare/DH_4092111

References and documents

Useful information

- Alzheimer's Society Factsheets http://alzheimers.org.uk/factsheets
- Symptoms and diagnosis – Alzheimer's Society info http://alzheimers.org.uk/site/scripts/documents.php?categoryID=200341
- Admiral Nursing Direct: www.dementiauk.org/what-we-do/admiral-nursing-direct/
- Leeds Directory www.leedsdirectory.org/ tel. 0113-391-8333
- This Is Me template- http://alzheimers.org.uk/site/scripts/download_info.php?fileID=849
- Making arrangements about mental capacity – e.g. lasting power of attorney https://www.gov.uk/power-of-attorney/overview
- Information about advance care planning www.goldstandardsframework.org.uk/AdvanceCarePlanning
- Information about cognitive stimulation therapy www.cstdementia.com/
- Leeds Centre for Integrated Living – support to use an individual budget for social care www.leedscil.org.uk/
- Advocacy for Mental Health and Dementia in Leeds - www.a4mhd.org.uk/our-services/
- Reducing the use of anti-psychotic drugs – Alzheimer's Society booklet - http://alzheimers.org.uk/site/scripts/download_info.php?fileID=1133
- Position statement on palliative care - Alzheimer's Society www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=428
- Leeds Safeguarding Adults Partnership www.leedssafeguardingadults.org.uk/

Experiences of people and carers living with dementia

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- Perspectives On Ageing With Dementia – Joseph Rowntree Foundation (2012) www.jrf.org.uk/sites/files/jrf/ageing-and-dementia-summary.pdf
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- Interview with Barbara Pointon, The Guardian (2007) www.guardian.co.uk/society/2007/dec/12/dementiacare
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- Quality Outcomes for People with Dementia (2010) www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119827

- The Right Prescription: A call to ACTION on the use of anti-psychotic drugs for people with dementia (NHS Institute (2011). www.institute.nhs.uk/qipp/calls_to_ACTION/Dementia_and_antipsychotic_drugs.html
- NICE Clinical Guideline 42 – supporting people with dementia and their carers in health and social care (2006). www.nice.org.uk/nicemedia/pdf/CG042NICEGuideline.pdf
- NICE dementia quality standard. www.nice.org.uk/guidance/qualitystandards/dementia/dementiaqualitystandard.jsp
- The Operating Framework for the NHS in England 2012-13. www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131428.pdf
- Dementia Commissioning Pack (DH 2011) www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_127381
- Using the Commissioning for Quality and Innovation (CQUIN) payment framework - Guidance on new national goals for 2012-13 (DH 2012) www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_133859.pdf
- Recognised, valued and supported – next steps for the carers' strategy – Dept. of Health (2010) www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_122393.pdf
- Nothing Ventured, Nothing Gained – risk guidance for people with dementia. Jill Manthorpe and Jo Moriarty (DH 2010). www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_121493.pdf
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- The State of Health Care and Adult Social Care In England in 2011-12 (Care Quality Commission 2013). www.cqc.org.uk/sites/default/files/media/documents/cqc__soc_201112_final_tag.pdf

Evidence and policy

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- Quality outcomes for people with dementia – progress across Yorkshire and the Humber (Regional Dementia Programme, 2011) www.yorksandhumber.nhs.uk/document.php?o=7148
- A Misspent Opportunity (All-Party Parliamentary Group 2010) http://alzheimers.org.uk/site/scripts/download_info.php?fileID=884&categoryID=200312
- Improving Dementia Services in England (National Audit Office, 2010) http://www.nao.org.uk/publications/0910/improving_dementia_services.aspx
- Leeds Partnership for Older People Pilot: Whole system change in later life mental health (Mary Godfrey, Leeds Institute for Health Sciences, 2009)
- Report of the Dementia Data Analysis Task Group (NHS Leeds internal report 2010)
- Guidance for commissioners of dementia services (Royal College of Psychiatrists / Joint Commissioning Panel for Mental Health, 2012) www.rcpsych.ac.uk/pdf/JCP-MH%20dementia%20(March%202012).pdf
- Dementia Diagnosis Resource Pack (NHS COmmissioning Board / NHS South of England, 2012) http://www.dementiapartnerships.org.uk/wp-content/uploads/DPC-resource-pack-v1.pdf
- Long-term conditions and Year of Care model – presentation by Sir John Oldham (2013) - http://www.kingsfund.org.uk/sites/files/kf/sir-john-oldham-year-of-care-capitation-payments-jan13.pdf

A-Z of dementia

- The Alzheimer's Society's "A-Z" of "bite size information on a variety of dementia related topics": http://www.alzheimers.org.uk/site/scripts/az_home.php?categoryID=200361