

LIVING WELL WITH DEMENTIA IN LEEDS

*Our local strategy
2012-15*



First published draft, June 25th 2012
Open for comment to 30th September 2012

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The artwork in this document is from The Living Story project, led by Artlink West Yorkshire, 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 Artlink West Yorkshire.

<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 Foreword

What are our priorities in Leeds to support people with dementia, families and other carers to live well? Recent years have seen the publication of important policy from the current and previous governments: The National Dementia Strategy (2009), Quality Outcomes For People With Dementia (2010) and The Prime Minister's Challenge On Dementia (2012). This document sets out our local response.

There is a shared, positive, vision to transform health and social care for people with dementia by investing in early diagnosis, information and support. People will stay well for longer, and admissions to hospital and care homes reduced, if we support people early.

The national policy sets out how standards must be raised and services improved. Staff working with older people are too often not supported with the right awareness and training. Anti-psychotic medication is too often the first option to manage distress and behaviour, and too often prescriptions are not reviewed. Too little is spent on research, not only to prevent and treat dementia, but to improve our understanding of the best support and care.

Change must go beyond health and social care, into our everyday lives. We can achieve a 'dementia-friendly' Leeds - the city, towns and villages - by listening to people's experiences, and working together to make changes. We have made and sustained many improvements in recent years. But there is more to do. We hope that many people and organisations will comment on this early draft, to influence and shape our work; and that local providers and organisations will set out their own plans to support people to live well with dementia in Leeds.

Tim Sanders, Joint commissioning lead for dementia, May 2012
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Timetable for this strategy:

- Open for comment and discussion until the end of September 2012.
- This document and a questionnaire can be found at www.leeds.nhs.uk/consultations
- Please contact Tim Sanders (see above) if you would like a speaker at a meeting about the strategy.
- This document will be amended to reflect these contributions, along with updates / progress.
- Strategy document and Leeds dementia action plan will be published in autumn 2012.
- The action plan will be kept up-to-date to show progress, and the strategy will be revised annually.

2 Our vision, values and approach

Once you have met a person with dementia,
you have met one person with dementia

Tom Kitwood

2.1 A strategy brings 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 of people with dementia. Our proposed vision for Leeds is that:

People and families affected by dementia will experience excellent support, treatment and care, throughout the 'dementia journey' and from all local services; and find that people are understanding and helpful in everyday life. We will benefit from:

- A voice for people living with dementia that genuinely influences local services.
- Living in a place which is 'dementia-friendly'.
- A helpful experience of early detection and diagnosis, with honest and timely conversations about what to expect.
- Support for the journey - a named contact person, who gives useful information and advice, and makes sure that services work together.
- A health and social care workforce with the right approach, skills and understanding.
- Wise investment in treatment and care that works to keep us as well as possible, reducing admissions to hospitals and care homes.
- The best possible experience of dying with or from dementia, with support when necessary from specialist palliative care.

2.2 This is the first published version of this new dementia strategy for Leeds. It is a draft open for comment and discussion, until the end of September 2012. This gives an opportunity for people and organisations to comment and influence what we do. It looks at our strengths and weaknesses, highlighting actions for what we need to improve quality of life and services in Leeds. This strategy should help service providers to work together, plan, make investment decisions and design services.

2.3 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, as leaders, grandparents, volunteers, unpaid carers. As we grow older, we might wish to continue with activities that we've always enjoyed, 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 and celebrate who we are and what we can do.

2.4 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 Trusts; Leeds City Council (Adult Social Care); the local Alzheimer's Society, Leeds Older People's Forum and other voluntary

sector representatives; Leeds Care Association (private sector care providers). Representation of people with dementia and carers is being developed through the Community Dementia Forum, supported by Leeds Alzheimer's Society.

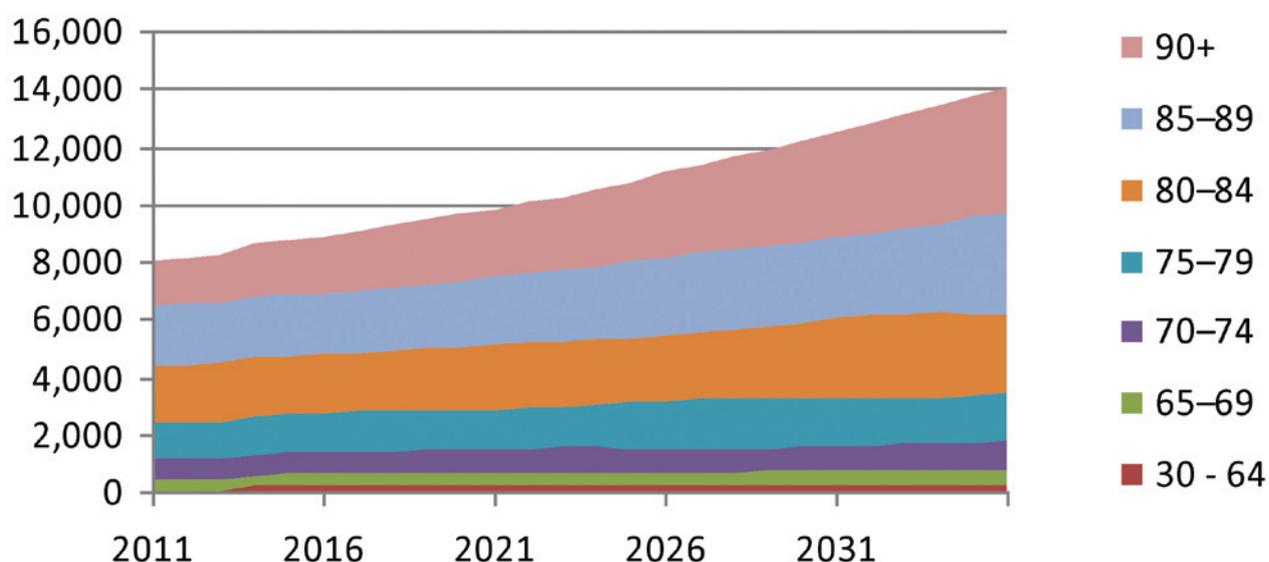
- 2.5 This strategy comes at a time of pressure on public spending, when local authorities face cuts, and the National Health Service, although offered some protection from cuts, is still expected to find efficiencies to meet increased demand for health services. We propose that supporting people early, 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.
- 2.6 There are an estimated 8,400 people with dementia in Leeds in 2012. This figure comes from research evidence which tells us how prevalent dementia is, applied to the local population figures. It is just under 8% of the people aged 65 and over in Leeds. This is likely to increase to 11,900 in 2027 – a 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 below in Box 1 and Figure 1:

BOX 1 - PEOPLE WITH DEMENTIA IN LEEDS

- Just over 5,000 people of the 8,400 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.
- 45% are diagnosed formally and on GP registers; others may be known to services without a formal diagnosis; many will be coping, or not, without support from services.
- Approximately 5,600 people of the 8,400 live at home, 2,800 in care homes.
- 200 people of the 8,400 are aged 64 and under.
- People with learning disabilities, especially Down's Syndrome, are at increased risk of developing dementia, along with other age-related conditions, 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.
- Prevalence increases with age, so people with dementia may often have other long-term conditions associated with the ageing process, and sensory impairments.
- It is estimated that 25% of all hospital admissions are older people with dementia, with the most common reasons including fractures, respiratory and urinary infections.
- 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.
- With Alzheimer's Disease, the time from onset until death is an average of about 8 years; with vascular dementia it is about 4 years, because of the link with heart conditions and strokes.

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

Figure 1 - People with dementia in Leeds, by age band



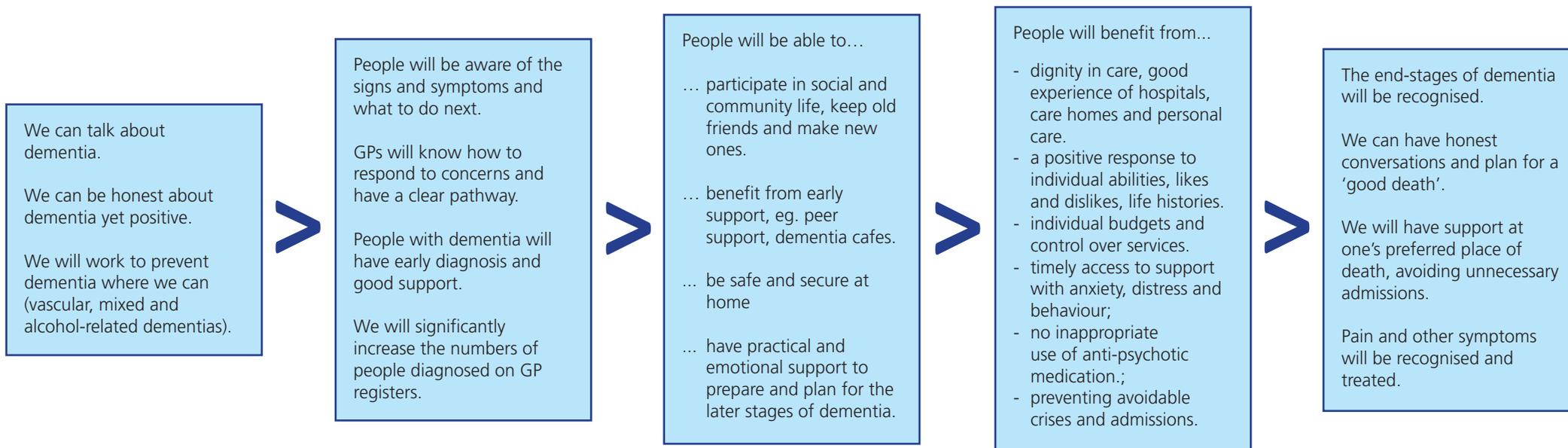
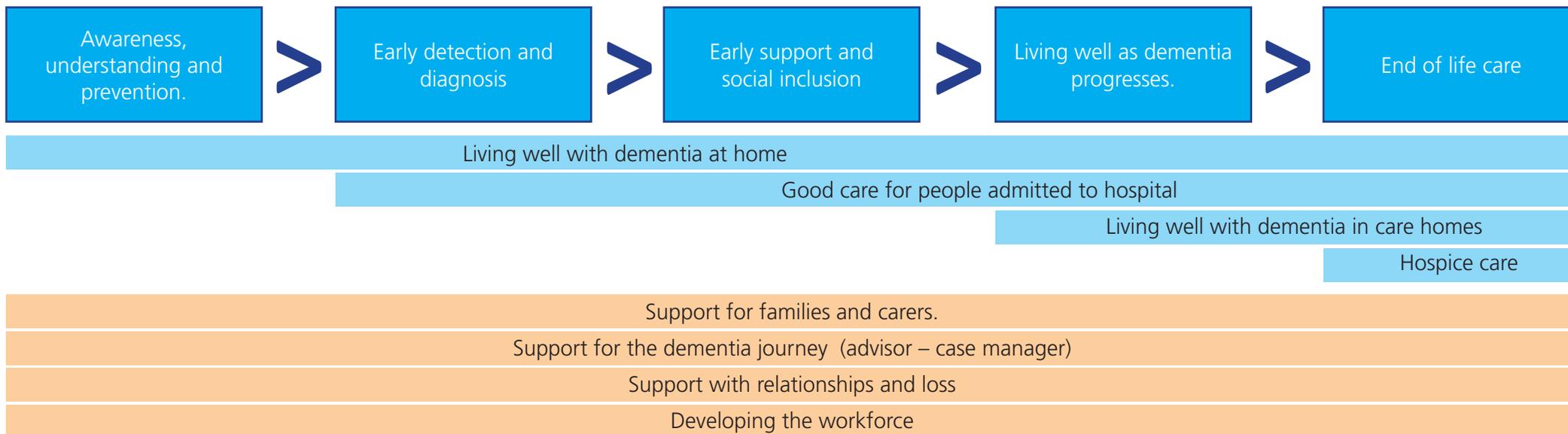
- 2.7 How dementia affects the person depends on an individual's life-history, relationships and psychology, alongside the progress of dementia and other health conditions. One size does not fit all for people with dementia. Therefore, health and social care policies which promote 'personalisation' offer opportunities for better care and support for people with dementia.
- 2.8 This introduction does not go into definitions of dementia, and this document is not intended to give clinical information about dementia. This is because its purpose is to plan and improve services. However, the 'Reference' section at the back shows where to find useful information.
- 2.9 The 'dementia journey' and how it should look in Leeds, is 'mapped out' on Page 6. It is intended to help us think about what we have working well in Leeds, and what is missing. The following chapters consider each stage of the journey.

NEXT STEPS:

- To improve our understanding of the Leeds population and how current services are used, by completing a 'dementia needs assessment' for the Leeds population.

The 'Dementia Journey' in Leeds

A way to think about living well with dementia



3 The views of people with dementia, families and carers

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

- 3.1 Although Leeds has some excellent examples of involving older people, and people with long-term health conditions, in planning services, this is not an area of strength regarding people with dementia. It is important to support and develop local involvement of people and carers, and is part of our commitment to the National Dementia Declaration.
- 3.2 Investment in early intervention, such as memory clinics, peer support and dementia cafes, has been very much valued. We have anecdotal but powerful examples of people saying how difficult the first steps are, to be concerned about dementia and seek a diagnosis; but that diagnosis and support has helped.
- 3.3 The Alzheimer's Society has recently published results of 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 had to wait five years or over for a diagnosis.
- 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.

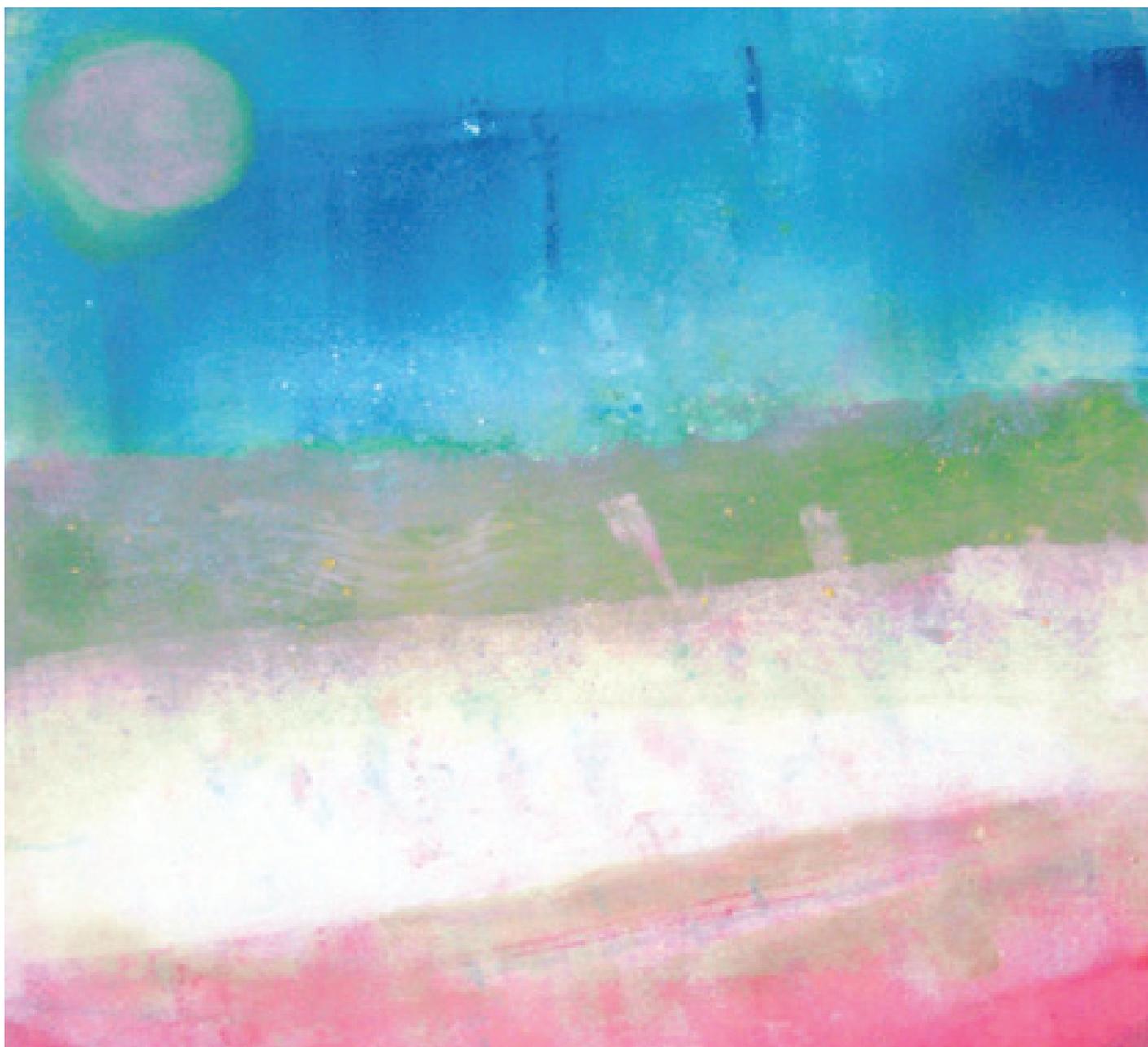
Dementia 2012 report - Alzheimer's Society

- 3.4 Initial conversations with the Leeds Alzheimer's Society's Community Dementia Forum, suggest that people are positive about the idea of a "dementia-friendly" Leeds, and defining what this means; and that carers have often been through times of feeling unsupported and isolated. There were comments indicating that, before finding out about the local Alzheimer's Society, people had felt isolated, and that 'support for the dementia journey' had been lacking.

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.

NEXT STEPS:

- To work with the local Alzheimer's Society to develop the Community Dementia Forum, and include Leeds Involving People in this work.
- For all service providers to ensure service-user involvement for people with dementia.



4 Dementia-friendly Leeds

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
- 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

- 4.1 Leeds has signed up to become a 'dementia-friendly' city, in response to a call from the national Alzheimer's Society, supported by the Department of Health. This is not a 'quick fix' but requires a sustained approach over 1-2 years and beyond, working with the Dementia Action Alliance to define and achieve the standards set.
- 4.2 The greatest barrier faced by people with dementia is probably stigma and negative attitudes to dementia. This is perhaps a combination of the stigma faced by older people and people with mental health needs. For example, a supermarket being unsympathetic to people who inadvertently forget to pay for goods; a bus driver refusing to let someone on the bus. However, there could be physical and environmental issues too – e.g. pubs and cafes with a lot of background noise; poorly-designed interiors and 'street-scene' which cause disorientation.
- 4.3 Leeds Library Services have already taken initiatives such as drop-ins at Pudsey Library and Leeds Central Library, for people with concerns about dementia to seek advice. Libraries have resources for people to eg. learn, communicate, reminisce, and have quiet space not far from our busiest places.
- 4.4 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 priorities proposed from this discussion are:
 - Target a local supermarket to become dementia-friendly, including staff awareness, practicalities such as seating.
 - Intergenerational work.
 - Consider a card or "passport", which can be shown as a way to obtain understanding and support.

The benefits of a dementia-friendly and aware Leeds, are that people will feel less stigmatised, more able to seek and find help, and less isolated.

NEXT STEPS:

- Involving local supermarkets and bus companies by developing simple statements of what they need to do to become dementia-friendly.
- Include dementia in local plans for intergenerational work.
- Planning local publicity and promotion for dementia-friendly Leeds.
- Ask town and parish councils to support the dementia friendly initiative.

5 Prevention and research

Factors that can increase a person's risk of developing vascular dementia include... a lack of physical activity, drinking more than recommended levels of alcohol, smoking, eating a fatty diet, or leaving conditions such as high blood pressure or diabetes untreated

Alzheimer's Society Factsheet

- 5.1 Alzheimer's Disease is the cause of most dementia, and the risk of developing this and most other types of dementia, are mainly related to age. There is information available (e.g. from the Alzheimer's Society website and the NICE Clinical Guideline 42) about the risk factors and causes of Alzheimer's and other types of dementia.
- 5.2 Life expectancy is longer in the more affluent, rural areas of Leeds, and so most local people with dementia live in these areas. This is in contrast to other mental health conditions, which are more prevalent in more deprived urban areas. It means that many people with dementia are self-funding for social care services, and might miss out on opportunities for information, advice and assessment, which are free of charge.
- 5.3 The next most common cause of dementia is vascular dementia. This is linked to heart disease and stroke, and therefore to the public health priorities regarding alcohol, tobacco, healthy eating and exercise. Local figures show that at any given age, people in more deprived areas of Leeds are slightly more likely to have dementia. It seems likely that this is linked to the impact of health inequalities on vascular dementia.
- 5.4 New funding has been announced, as part of The Prime Minister's Challenge on Dementia, for research into dementia – covering care as well as prevention and treatment. This represents an opportunity for health and social care organisations, universities and community groups to work in partnership to develop projects and bid for funding.

The benefit of prevention is to reduce the numbers of people with vascular dementia compared to what we expect in future, which would in turn contain costs.

The benefits of participating in research is to improve and share our knowledge of what works and what we should invest in. People affected by dementia can benefit from new approaches to treatment and care, and from making a positive contribution to knowledge about dementia.

NEXT STEPS:

- To aim for at least one new research project funded from *The Prime Minister's Challenge*, to be located in Leeds.

6 Early detection and diagnosis

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

- 6.1 Diagnosis of dementia in Leeds is via the Memory Clinic service, provided by the Leeds and York Partnership Foundation Trust (LYPFT). General Practitioners (GPs) are able to refer people to a memory clinic where there is concern about possible dementia. This usually follows discussion of concerns with the person and family; a short cognitive test; and screening for other possible conditions.
- 6.2 People with learning disabilities (LD) who develop possible symptoms of dementia require a specialist service. This is provided by LYPFT's services for people with learning disabilities, working with colleagues in dementia services as required.
- 6.3 The number of people diagnosed with dementia in Leeds is 47% of the number of people estimated to have the condition. This figure is from 2009-10, when 3,795 people were on GP registers with the diagnosis. This is slightly better than national average, but below the best-performing areas and below what we need, if we are to support people early in the journey and reduce need for more intensive services. Initial analysis of referrals from GPs to memory clinics suggests that there is local variation between localities within Leeds.
- 6.4 Therefore it is a high priority to ensure all local GPs have awareness and training regarding dementia, and in particular the referral process and pathway for memory clinic services.
- 6.5 It is possible that there are people with more advanced dementia, who are treated as having dementia, but have never had a formal diagnosis recorded. At the later stages, there is not always benefit in referring to memory clinic, and Royal College of Psychiatry guidance indicates that people may be diagnosed in primary care. We need to ensure that there is clarity for GPs about making and recording diagnosis in these circumstances.
- 6.6 The benefits of early diagnosis are becoming better understood and accepted. However, it is not easy to talk about dementia, or worries that one might have about it, even with close family and friends. It is natural to want to hang on to one's previous normality, and to be concerned about keeping eg. driving licence and travel insurance. We must appreciate the obstacles and difficulties that prevent people seeking help. Memory services in Doncaster have interviewed people using their services, and found that it can take a year before concerns about (e.g.) forgetfulness are discussed with a close family member, and a further year before concerns are raised with a health professional.

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.

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

- 6.7 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. The normal ageing process can sometimes lead to a 'mild cognitive impairment' (MCI), when a person is perhaps more forgetful than average for one's age, but does not go on to develop

dementia. 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.

- 6.8 There is evidence that treatment with anti-dementia drugs can improve symptoms and slow the progression of dementia, for some people. Even a marginal benefit can boost confidence and quality of life. In Leeds, the recommendation to prescribe is made by the memory clinic service to the GP, after diagnosis.
- 6.9 People prescribed these drugs stay with the Memory Clinic service for review, though in other parts of the country there are 'shared care' guidelines which support GPs to be more involved. Locally, such guidelines could free up capacity of memory clinics to see new patients quickly, and thus improve our diagnosis rates in Leeds.
- 6.10 There is a national initiative to improve detection of dementia when people are admitted to hospital. This is because people with undiagnosed dementia are at particular risk of coming into services when there is a crisis, illness or injury, and likely to first present on admission to acute hospital. The initiative is the 'national dementia CQUIN', with CQUIN being short for "Commissioning for Quality and Innovation". Further details are in section 15, 'Good care for people admitted to general hospital'.
- 6.11 Detection and diagnosis is the key to offering early support, which is covered in section 8. We know from people living with dementia, that the onset of symptoms, seeking and receiving a diagnosis can be a dreadful time of loss and anxiety; but that it can be the first step to recovering one's well-being and quality of life.

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.

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

- 6.12 At the Leeds dementia event in May 2012, it was suggested that some groups of people might have difficulty accessing memory clinic services; eg. older people in prison, and people with other health conditions and disabilities. This will be investigated further in our dementia needs assessment.

The benefits of early diagnosis 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.
- the opportunity to have useful information, support and to take part in activities.
- the opportunity to prepare and plan ahead.

NEXT STEPS:

- Introduction of a clear pathway for diagnosis, and training for GPs to implement it.
- Clarify the position regarding diagnosis and recording when people present in the later stages of dementia.
- Consider 'shared care' arrangements for people taking anti-dementia drugs, whether memory clinic capacity can be better used.

7 Support for the dementia journey

People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care, that identifies a named care coordinator and addresses their individual needs.

NICE quality standard for dementia

- 7.1 People with dementia, families and carers, are highly complimentary towards staff and services which offer information, advice and support, such as the Alzheimer's Society. However, this praise is often in the context of how long it took to find out about this support, and how difficult life was beforehand. In the past twenty years, social care and support services have been designed more and more to provide short-term interventions, because it is always necessary to allow for new people and new referrals. However, dementia is a long-term condition which requires advice and support at the start, and to be available as required throughout the journey.
- 7.2 Often the support required at any one time can be 'low-level' but important; e.g. being put in touch with a peer support group or dementia café when lonely and isolated; advice on how to ask for a break from caring, support to stay in work or which benefits can be claimed. Further on in the dementia journey, it might be that a family member contacts the GP to say that a person is becoming distressed, or the sleep pattern is disturbed, and more specialist help is needed.

You are left alone just doing the best you can

Shirley Nurock, from London - interviewed for BBC News item, 2007

- 7.3 Specialist mental health services reach a minority of people with dementia. Community Mental Health Teams provide specialist support, providing a care co-ordinator role under the Care Programme Approach (CPA). National research suggests perhaps 25% of people with dementia benefit from such a service at some point in the dementia journey; we will gather local data to see if the picture is similar in Leeds.
- 7.4 Therefore, in Leeds we have a gap in services, particularly after a person is discharged from the memory clinic service. There are different models of support and care which could potentially fill this gap, but it is important we do the right thing to fit with local needs and services, and make a strong case that new investment would lead to better outcomes for people, and future savings eg. from reduced hospital and care home admissions.
- 7.5 The role of 'dementia adviser' was piloted in 22 places around the country as part of introducing the National Dementia Strategy, and a national evaluation is due from Newcastle University in autumn 2012. The Leeds branch of the Alzheimer's Society has created two part-time dementia advisor posts. The organisation Dementia UK promotes the role of the 'Admiral Nurse', which is available in 3 areas of Yorkshire and Humberside (Hull, Kirklees and North Lincs). Dementia UK also offer a national Admiral Nurse helpline. The Department of Health has proposed a service model to support the management of dementia as a long-term condition in primary care (GP practices). This is *Service specification for dementia: better care at home, and in care homes*, part of the Dementia Commissioning Pack published in 2011.

7.6 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' – an approach called 'risk stratification' that identifies who is most at risk in the local population;
- 'Enable Me' – promoting self-management, involving the person with the condition, family, community groups, and supported by staff;
- 'Support Me' – integrated teams providing health and social care;
- and, at all of these stages, 'Decide with me'.

7.7 It is important that people with dementia can benefit from this new approach, whether dementia is the main reason for needing support, or whether it is alongside ('co-morbid' with) other long-term conditions. It is therefore proposed that a Leeds model of support for the dementia journey, should be one that supports the person with dementia and family / carers; and that works collaboratively with other services.

Benefits of support for the dementia journey:

- People will not be left alone with a diagnosis of dementia and without a named contact.
- It will support compliance with NICE quality standard for dementia.
- The potential to work collaboratively to support people with different 'co-morbid' long-term conditions.
- The potential to maintain well-being and reduce costs of care.

NEXT STEPS:

- Ensure that our work on integrated management of long-term conditions, includes the needs of people with dementia.
- Develop a service model to provide support throughout the dementia journey which supports the Leeds model of integrated health and social care.
- Develop a 'business case' to invest in the service model.



8 Early support and social inclusion

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.

- 8.1 In Leeds we have invested in a range of services that offer support to people affected by dementia, which offer activities and support at a time when people are at high risk of losing touch with family, friends and community. The services specific for dementia include dementia cafes and peer support networks. We have worked with the local Alzheimer's Society and our Neighbourhood Network groups to offer activities such as 'Singing For The Brain', and reminiscence. Leeds Memory Clinics offer additional support to cope and adapt. The memory clinics and the Leeds peer support network offer cognitive stimulation therapy, which aims to stimulate and engage people with dementia, and offers the social benefits of a group.
- 8.2 It is important for people with dementia to continue to access community activities and services aimed at all age groups and older people, regardless of the dementia. This includes intergenerational activities. Such approaches are similar to local work to develop 'self management' of long-term conditions. In both cases, we are looking to support voluntary, community and faith groups (the 'third sector') to build capacity to support people living with health conditions.
- 8.3 We have powerful testimonies of how important such services can be; but at the moment they only reach a few hundred people, relatively small in scale compared to the local challenge we face. Some activities and groups have to sustain themselves on short-term funding.

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, member of Leeds peer support network

- 8.4 Housing-related support services can offer important help e.g. to maintain tenancies, stay safe and to access activities. In Leeds, Creative Support provide a 'floating support' service (i.e. the service comes to where you live, and does not require the person to move into sheltered housing to receive it).
- 8.5 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, thinking about what treatment one would and wouldn't want in future (Advance Care Planning), writing down one's likes and dislikes and personal "dos and don'ts", using e.g. the Alzheimer's Society's *This Is Me* template.

- 8.6 Early support services may have a broader role to play, in supporting people to seek a diagnosis and access the right health services. Therefore, support should have a flexible approach and not depend rigorously on receiving a diagnosis before help is offered. We know that dementia is difficult to talk about, whether with family, friends or health professionals. Community-based groups and services can therefore play a valuable role pre-diagnosis. For people who live alone, community groups might be the first to notice that possible signs and symptoms of dementia are developing.
- 8.7 It is difficult to assess the impact and financial benefits of early interventions, e.g. how do we know that an intervention today will work to keep someone in better health than might otherwise be the case, and prevent a hospital admission? How would we know this even in a few years' time? This means commissioners must accept a level of risk regarding the financial return from investing in early support, and accept that people with dementia and carers value it highly.

The benefits of early support:

- People can sustain and recover social life and friendships.
- There is evidence that people feel less depressed after joining a dementia café or activity group.
- People are more likely to get to know important information and access other services.
- Carers can have a break, someone to talk to and access useful information.

NEXT STEPS:

- Complete the 'Good Ideas For Dementia' small grants process, and evaluate the results.
- Develop a joined-up approach for dementia alongside other long-term conditions; an ambitious approach to developing early support and self-management.



9 Support for families and carers and support with relationships

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

- 9.1 Carer support is addressed at national policy level by *Recognised, valued and supported – next steps for the carers' strategy*. Carers are "the first line of prevention", according to the governments *Vision for Adult Social Care*. Improving support for carers is essential to the well-being of both carers, and people with dementia who rely on care from family, neighbours and friends. 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.
- 9.2 Carers of people with dementia, as with other long-term conditions, are best identified 'at source', when diagnosis is made. GP practices in Leeds use the 'yellow card' scheme in partnership with Carers Leeds, to identify and record that a person is a carer, and to link to the offer of support and information from Carers Leeds.
- 9.3 Carers often 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 (especially 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.
- 9.4 Carers Leeds and the Leeds Alzheimer's Society have each recently appointed a dementia carer support worker, to strengthen our local offer of support. The dementia café model in Leeds is especially aimed to support carers, who nevertheless can bring the person with dementia to the café if so wished. This service is valued, but some initial support is needed to develop further cafes and ensure a consistent standard of service.

"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

- 9.5 Carers require skills and training, usually knowing little or nothing about dementia before finding oneself in the caring role. 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. Family members of people with dementia often have to take on managing a person's financial affairs, and this requires specific information and advice, to make the legalities and practicalities less complex.

- 9.6 Leeds Shared Lives is a carer support service which offers the chance to leave the house for a few hours, or overnight, and a shared lives worker stays with the person. 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. The person with dementia does not have to go into an unfamiliar environment.
- 9.7 The Shared Lives service is valued as an early intervention which can provide social connection and activity for the person cared-for, as well as a break for the carer. It can be accessed in Leeds without going through an assessment and eligibility process, and has recently been supported through carer breaks funding via the NHS. It offers peace of mind for carers, knowing that the person with dementia has someone there. The service is registered to provide personal care if needed. The service is looking to increase short break provision where the person with dementia goes to stay in the home of a Shared Lives paid carer.
- 9.8 Other carer break services are accessed via social care assessment, which includes the entitlement for 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 many Council-run services being closed or proposed for closure. The local private sector can offer good quality nursing and residential care and sufficient vacancies for short-stays, but there is no block purchasing of respite beds, which can make it difficult to book each stay consistently in the same home.
- 9.9 Family carers especially can experience a strong sense of loss and impact of dementia on relationships; bereavement can seem a drawn-out process with upsetting events and emotional challenges before as well as after the death of a loved one. Carers can need someone to talk to as much as, or even more than, practical support or a break from caring. Relationship counselling has not been offered specifically for people with dementia and carers in Leeds. Where this has been piloted, there seems to be some reluctance to taking up the offer, but good outcomes for small numbers of people who do.
- 9.10 Carers express the wish to have information and understand about the cared-for person's health conditions, to better help the person cared-for; to be treated as expert partners in care.

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.

NEXT STEPS:

- Funding for a short-term post to develop and co-ordinate the dementia café network.
- Identify and record carers of people with dementia, taking the opportunity of a new social care record system, to identify the extent of carer support and carers' assessments.

10 Staying safe and secure at home

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)

- 10.1 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.
- 10.2 West Yorkshire Fire and Rescue Service offer home visits for vulnerable people for fire safety checks. Trading Standards offer advice to prevent 'scams' and doorstep crime, which people with dementia can be especially vulnerable to; they work with local Neighbourhood Watch schemes and there are local examples of "No Cold Calling" zones, for example in areas of Otley, funded by the town council. The Telecare service can provide 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 eg. help assess for hazards and fit equipment and minor adaptations to reduce risk of falls; or improve home security. Staff working for these and other organisations, who provide services to improve safety at home, are likely to require dementia awareness training to deliver an effective service.
- 10.3 Getting out and about can lead to safety concerns, whether driving, crossing roads as a pedestrian, or the risk of getting lost. How early in a person's dementia this causes difficulties depends very much on the person and the individual progress of the dementia; although a diagnosis of dementia must be notified to the DVLA and car insurance provider. The Alzheimer's Society publishes a factsheet on driving, and the William Merritt Centre in Leeds is a driving assessment centre.
- 10.4 There is potential for organisations to work together for a more integrated and routine approach. Safety and security was a workshop topic at the Leeds dementia event in May 2012, and some participants expressed surprise about what is available and they weren't aware of. There is potential to be more systematic so that people with dementia benefit from simple, cost-effective support. Housing-related support services and neighbourhood network groups could play an important role in enabling people to access help.
- 10.5 It is important to think in a person-centred way about safety and managing risks. For example, opportunities to go out walking or exercise with a group can help a person to feel tired and ready to rest, rather than go out alone. This is an important subject for training and awareness, for both families / unpaid carers, and the paid workforce.
- 10.6 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. There is no separate arrangement for people with dementia. We will include safeguarding in the local dementia needs analysis, to understand how current arrangements are working for people with dementia.

The benefits of improving support for safety and security are:

- Easier routes to resolve concerns for people with dementia and families.
- Reduced incidence of serious incidents and injury.
- Increased confidence that people can stay at home, in familiar environment.

NEXT STEPS:

- Develop dementia awareness training for staff outside health and social care.
- Work with Trading Standards and Neighbourhood Watch to consider success and extension of “No Cold Calling” zones.
- Consider how safety and security support can be promoted and made easier to access.



11 Developing the workforce

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

NICE quality standard

11.1 The quality and sympathy of staff comes up time and again in conversations about older people's experiences of treatment and care, and particularly care of people with dementia. The right values, attitudes, skills and knowledge for dementia care are necessary to provide dignity in care, and good outcomes from treatment and care.

11.2 Very simple and small changes can make a huge difference for people with dementia. 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 professional support – e.g. staff with strong medical skills in treatment and care for physical illness, can learn from working with liaison psychiatry 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

11.3 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.

11.4 Staff and volunteers offering social activity and early support 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.

11.5 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 contribute to paid staff awareness and understanding.

11.6 Leeds has taken an innovative approach to dementia training, with managers and staff from adult social care, NHS providers, and independent sector, trained by Stirling University as leaders in dementia care, and as trainers who can offer training to staff and peers. Combined with training courses from external trainers, it means that staff have access to dementia training.

11.7 However, a systematic approach is needed to ensure the NICE quality standard is achieved. This is a huge challenge across our NHS Trusts and over 100 private sector providers working with older people. Local organisations are already taking the initiative, for example Leeds Care Association is auditing training for its members (private sector providers), Clinical Commissioning Groups are arranging training for GPs, and Leeds Teaching Hospital Trust has made dementia a high priority.

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.

NEXT STEPS:

- Implement the NICE quality standard by ensuring it is reinforced through contract management and auditing of the workforce.
- Develop an offer of training for voluntary, community and faith groups, including volunteers, to run from autumn 2012.



12 Living well with support and care

...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

- 12.1 It is important for our local plans, to consider the difficulties that people can face in the later stages of dementia. People with dementia at the earlier stages of the condition may, understandably, not want to look too far ahead; but will want to know that care services will be grounded in respect, dignity, and a person-centred approach.
- 12.2 Dementia is linked to some high costs of care. The basis of the National Dementia Strategy is that much of this could be prevented or delayed with the steps described in earlier sections of this document, giving a better life for the person at lower cost to services.
- 12.3 In 2010-11, there were over 94,000 unplanned admissions to hospital for people living in Leeds; there is evidence that 25% of people in hospital have dementia. This would put the annual cost in the region of £100m for people with dementia. Leeds City Council spends £80m per year on care home costs (before recovering contributions from people funded for care), and applying estimates of dementia prevalence in care homes suggests that £50m of this relates to people with dementia. These costs relate to dementia alongside the other health conditions and disabilities that may be the primary reasons for admission to hospital or a care home.
- 12.4 Both these figures are subject to the 'demographic pressure', which in Leeds is over 2% per year, as the numbers of people with dementia increase. This indicates that to do nothing would be a very costly option.
- 12.5 The progress of dementia will vary according to the individual, the type of dementia and how it develops. There are likely to be more physical needs – difficulties with mobility and needs for personal care – alongside increasing confusion. People can, understandably, become frustrated and easily upset, angry or aggressive, even if that was never one's nature before the illness. The caring role can become much more difficult, as the cared-for person not only needs more help, but less able to understand and co-operate.
- 12.6 However, it should not be assumed that every sign of decline is part of irreversible progress of dementia. One does not have to have dementia to become more angry or irrational if we're tired, in pain, or just having a bad day. People with mild dementia might become 'stuck' because of forgetting one link

in a sequence of tasks, and just need a small prompt. The ability to adapt to unfamiliar surroundings can make dementia look much worse when still at an early stage.

- 12.7 People with dementia are vulnerable to abuse and neglect, especially in the later stages when most reliant on other people, and having difficulties with communication. Safeguarding concerns may arise from very poor quality of care and lack of training for staff. Safeguarding arrangements are referenced in section 10 of this document (Staying Safe and Secure At Home).

Creative and therapeutic approaches

- 12.8 People with dementia may find it increasingly hard as the condition progresses, to communicate with others, express feelings, and to be stimulated and occupied. This can have a profound impact on one's sense of well-being and self-esteem. There is some evidence from different projects that engage people in creative activities, that people can appear happier, talk more, and show less frustration and aggression. Our Leeds dementia event in May 2012 included workshops on creative arts, singing for the brain, reading aloud and hand massage.

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)

- 12.9 We will continue to support and promote opportunities for people with dementia, families, volunteers and staff to benefit from such approaches, and to evaluate effectiveness. People who are healthy can 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.

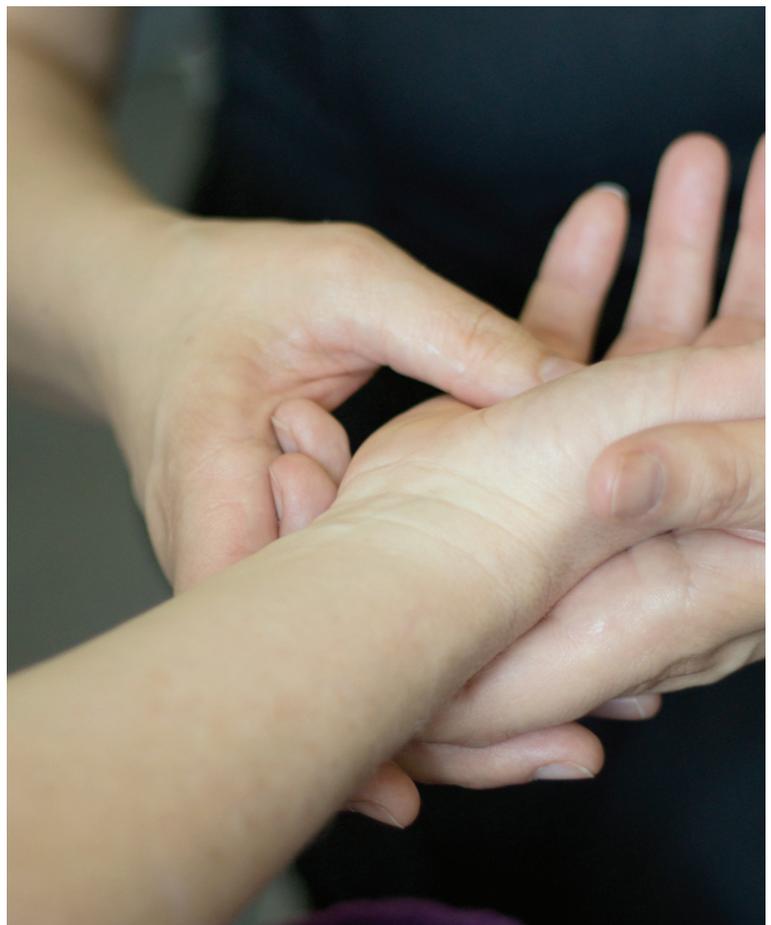
Specialist or 'Secondary' NHS Services

- 12.10 In Leeds, the Leeds and York Partnership Foundation Trust (LYPFT) provides secondary mental health services, including specialist services for people with dementia. LYPFT is in the process of reconfiguring its services, which includes working-age adults and older people supported by new teams, rather than separate teams for different age groups. This is due to go 'live' in June 2012.

- 12.11 Community Mental Health Teams (CMHTs) provide specialist support for people with mental health needs, including dementia. Support is provided under a 'Care Programme Approach', when a person needs 'co-ordinated support to help with engagement and maintaining safety'. and includes a specific team for younger people with dementia. Our local dementia needs assessment will include information about usage of specialist services compared to the number of people in the later stages of dementia. Nationally, it is estimated that just 25% of people with dementia are supported by a CMHT at some point in the 'dementia journey'.
- 12.12 LYPFT provides support to people living at home including intermediate care and crisis support which aims to avoid admission to hospitals and care homes. These services and teams are part of the transformation process. There is a specific care homes team which works with care home staff to contribute to individual care planning and resolve difficulties, whilst developing the skills of staff.

Adult social care and self-directed support

- 12.13 Leeds City Council adult social care offers a range of direct provision, including peer support; the Shared Lives services; mental health enablement and support at home, day care; short-stay residential beds; and Care in the Community (CIC) beds used as an alternative to hospital and to promote early discharge.
- 12.14 The great majority of adult social care is provided by private sector organisations, under contract to Leeds City Council. The needs of people with dementia will be specifically addressed as new service specifications and quality standards are developed, and by working with all providers to develop the local workforce.
- 12.15 Person-centred care may be greatly improved by 'self-directed support', which uses an individual budget for social care. This is an initiative for all adults with care needs, and it is important that people with dementia and carers have the support to benefit to the full from this initiative. As dementia progresses, needs for personal care, 'watching over' and social stimulation can reach the level of eligibility for social care. This depends on an assessment process for the person with dementia and any carers. Self-directed support gives more flexibility, e.g. to choose who comes to help with one's personal care in the morning, and perhaps then to help get out and about and enjoy social opportunities.
- 12.16 People with dementia and families can face very tough choices when it is becoming difficult to support a person in one's own home. Leeds City Council adult social care and social



housing providers have developed local extra-care housing schemes, which can provide an alternative to residential care, with 24-hour care available on site, but in a standard tenancy or leasehold arrangement, including the opportunity for couples to stay together (when residential care would lead to living apart). There have been local and national examples of successful extra-care provision for people with dementia, though some difficulties reported in meeting very specialist needs.

- 12.17 Many people with dementia live in the more rural and suburban areas around the city, and there is a significant number who self-fund for social care. The providers in the care home and retirement housing markets already understand and respond to this, and there are opportunities for alternatives to flourish, which can support people to stay at home.
- 12.18 In Leeds, the Centre for Integrated Living (CIL) helps people to plan support, either with one's own money and / or from an individual budget from adult social care. CIL has supported people with dementia – albeit so far, relatively small numbers – to recruit personal assistants and benefit from more flexible care.

N. is aged over 85 and lives in Leeds, with family some distance away. As N's condition has progressed her family were considering whether she needs residential care. She has support at meal times and the same staff take her to attend a social group a couple of times a week, which is more flexible than a traditional home care service would be. This is funded by a Direct Payment, paid into a Managed Bank Account which Leeds CIL provides. This support has been in place for almost a year and N has remained in her own home.

From Leeds Centre for Integrated Living (CIL), Feb 2012

Advocacy

- 12.19 Advocacy services can be very important for people with dementia, because as the condition progresses it becomes increasingly hard to weigh up information, make decisions and communicate one's wishes and feelings. In Leeds, Advocacy for Mental Health and Dementia (A4MHD) are the current providers of dementia advocacy. People with dementia who are considered for serious medical treatment or moves to care homes, must be considered for Independent Mental Health Advocacy service (IMCA).

Continuing Healthcare

- 12.20 People with dementia may qualify for NHS Continuing Healthcare; this is when a person's ongoing health and carer needs meet specific criteria, to qualify to be arranged and funded solely by the NHS. NHS continuing care is provided free of charge. Nationally, this has proved to be a complex and difficult issue, with disputes about eligibility and the conduct of the assessment process. The Alzheimer's Society publishes advice and has national group on the issue. Our dementia needs assessment in Leeds will include local information on continuing healthcare.

Integrated health and social care

- 12.21 In Leeds, NHS and social care is developing an integrated approach based on "Find Me, Enable Me, Support Me, Decide With Me". This is discussed above in section 7, Support throughout the dementia journey. At the later stages of dementia, especially where people are living with other long-term conditions, there will be increasing numbers of frail older people with dementia and physical care needs linked to eg. mobility, nutrition, continence, and relatively high risk of admission

to hospital and care home. There are new integrated health and social care teams being set up to support the people most at risk. Our local strategy for people with dementia is to ensure a joined-up approach to people living with dementia plus other health conditions, maintaining well-being and independence as far as possible, as part of the new arrangements for integrated care.

Specific care issues and settings

12.22 The following sections of this strategy look specifically at responding to the behavioural and psychological symptoms of dementia, specifically the use of anti-psychotic medication; and people with dementia in care homes and hospital settings.

The benefits and aims of improved care and support are:

- Improving well-being by offering creative approaches and demonstrating effectiveness.
- Taking advantage of the opportunities for self-directed support.
- Preventing crises and increasing planned, preventive care and support.
- Reducing avoidable admissions to hospitals and care homes.

NEXT STEPS:

- Ensure that dementia is recorded on health and social care records, so we know more about people with dementia, use of services, and outcomes.
- Gather information from safeguarding, complaints and advocacy as part of dementia needs assessment.
- Working as part of the Leeds integration programme, to ensure that needs related to dementia can be met and staff are supported.
- Offering further training opportunities for creative approaches.

13 The Right Prescription – anti-psychotic medication

The inappropriate prescribing of antipsychotic medication can have significant consequences for the person. Antipsychotics can increase people's symptoms of dementia and cause dizziness and unsteadiness, leading to falls and injuries and robbing people of their quality of life.

The Right Prescription – Dementia Action Alliance and NHS Institute (2011)

- 13.1 At some point in the dementia journey, 90% of people (estimated) will experience the 'behavioural and psychological symptoms of dementia' (BPSD). The national 'Call To Action – The Right Prescription' is a response to concerns that:
- medication is used as a first-line, sometimes the only, response;
 - support to understand and reassure people, and change behaviour in a person-centred, 'psycho-social' way, is not available or offered;
 - the medication used, 'anti-psychotics', can have harmful effects, such as dizziness leading to falls and injury; and increased risk of suffering a stroke.
 - The guidance for prescribing this medication is not widely followed, which includes considering alternatives to medication; explaining the benefits and risks to the person and carer; and reviewing the prescription.
- 13.2 The reduction of such prescribing for people with dementia, is identified as a target in the NHS Operating Framework 2012-13, which states that a two-thirds reduction is required.
- 13.3 'Anti-psychotics' include risperidone, which is licensed for short-term use for BPSD. Others include chlorpromazine (Largactil), haloperidol (Haldol, Serenace), olanzapine (Zyprexa), and quetiapine (Seroquel). The evidence for the benefit of these drugs is more limited. In particular there is no evidence that quetiapine works in people with dementia. Most of these antipsychotic drugs are not licensed for people with dementia but are still used. This is not illegal. However, if a doctor uses these other antipsychotic drugs they must have a good reason (this is an extract from the Alzheimer's Society booklet, *Reducing the use of anti-psychotic drugs*, which has detailed information on the drugs and the alternatives, and what to do if you are concerned).
- 13.4 Perhaps 20% of people with dementia are being prescribed these drugs at any one time – this is the national estimate from the Call To Action. However, two audits in Leeds, with nearly complete coverage of GP practices and patients, have identified approx. 400 people of the 4,000 with a diagnosis of dementia – a figure of 10%. A repeat audit, which is underway (May 2012) has been amended to ask about people who are being prescribed anti-psychotics because of BPSD, but are not formally diagnosed.
- 13.5 The local audit is based on a step-by-step approach linked to the NICE Clinical Guideline (CG42) and its description of what should happen when prescription of anti-psychotics is being considered, before the drugs are prescribed, and review afterwards. Although it is a one-off audit, it could form the basis of a standing 'protocol' or 'algorithm' to be used at all times by GPs and in secondary care. It could

include the kind of 'flags' for review routinely used on GP systems with prescriptions for e.g. statins, or blood pressure treatment.

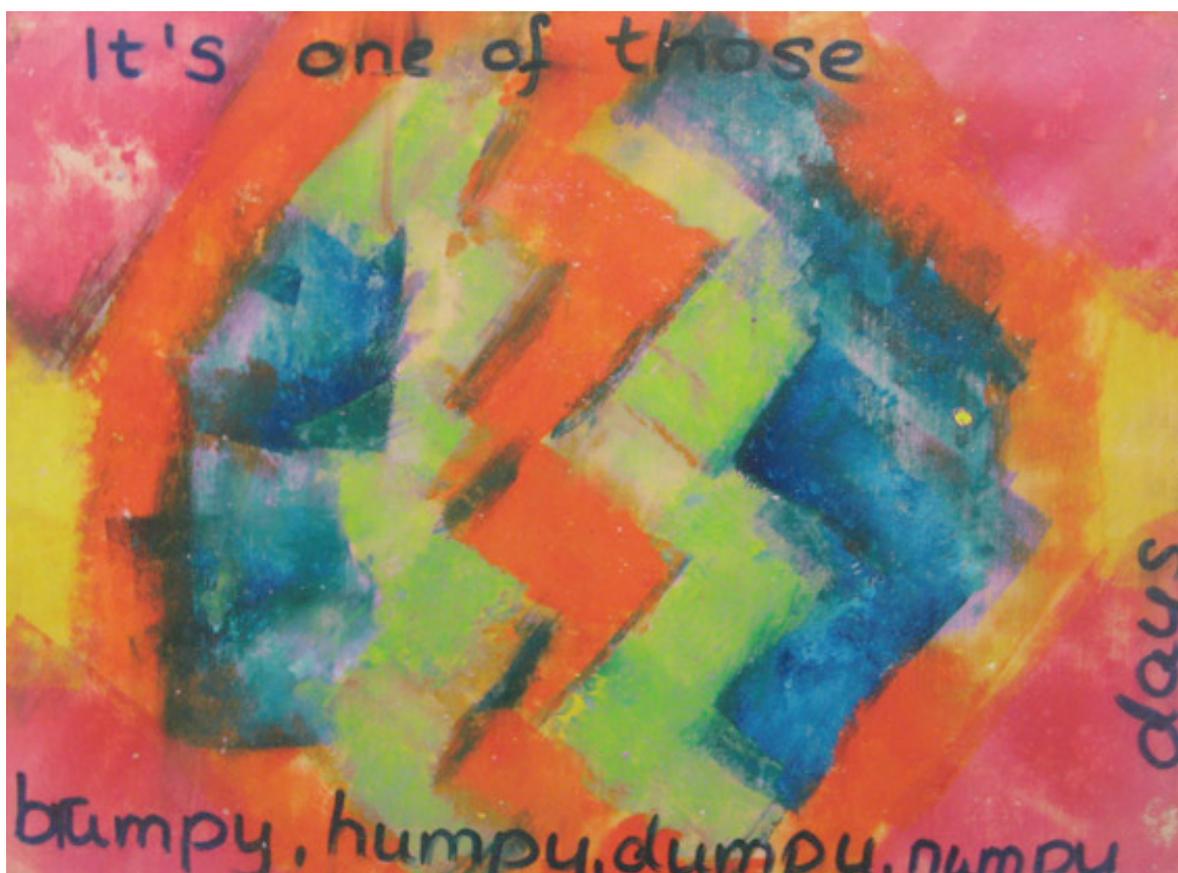
- 13.6 The lack of reviewing of the prescription is suspected to be a key issue locally. As people progress with dementia, behaviour can become more passive and the original reason for the prescription – whether it was appropriate or not – no longer applies. The lack of review may arise when the medication is prescribed in specialist care, and the person is discharged without the need for review being picked up; this may also happen when people move into the Leeds area from elsewhere, e.g. when moving into a care home.
- 13.7 A local GP practice has reviewed 23 people with a diagnosis of dementia who have been prescribed the medication, and was able to end the prescription for 21 people with no adverse effects. This supports the idea that there is a cohort of people where any rationale for prescribing no longer applies, and that significant reduction may be possible without improving access to alternative support.
- 13.8 Access to support with BPSD appears to be a problem in Leeds, and may vary according to locality and care setting. The NHS trust which provides specialist care, LYPFT, can offer services to people living at home through the Community Mental Health Teams (CMHTs); to people in general hospital through its liaison psychiatry team; and to people in care homes via a specific team linked to the CMHTs. It is likely that the support available in one's own home and in care homes is less than the numbers who could potentially benefit from such help; and sometimes it is difficult for services to respond quickly enough.
- 13.9 The initiative to review the medication can come from anyone and anywhere in the network of support and treatment. People with dementia and families, local community groups, care homes, other service providers and pharmacists can all ask a GP why medication has been prescribed and ask for it to be reviewed.
- 13.10 Support with BPSD and reducing anti-psychotic medication is an important role envisaged for the Department of Health's model for support to GPs (primary care). This is described in [Service specification for dementia: better care at home, and in care homes](#), which in this strategy is also referred to under section 7, Support for the dementia journey.
- 13.11 A task group has been set up for our local Call To Action, by the Leeds Area Prescribing Committee working with the Leeds Integrated Dementia Board. It will work over the course of 2012-13, to implement the reduction of anti-psychotic medication, to end inappropriate prescribing. Leeds has a share of national funding via the Strategic Health Authority to support this work, including innovative approaches.
- 13.12 This local task group includes a GP, medicines management lead, pharmacy leads from all local NHS trusts and community pharmacy, psychiatric nurses from the specialist care homes team. Leeds has pharmacists tasked with reviewing all prescribing for people in care homes, and they have taken the initiative to join this work specifically on anti-psychotics.
- 13.13 The group has identified concerns that the campaigning approach of the national Call To Action, should not prejudice the interests of people who may benefit from the medication. There is anecdotal information that the pressure to deal with BPSD combined with the guidance to avoid anti-psychotic prescribing, may be leading to use of other medication.

Benefits and aims of reducing anti-psychotic medication:

- Fewer strokes and falls arising from side-effects of medication.
- Improved access to alternative psycho-social approaches.
- Reduced costs of prescribing where inappropriate use is stopped.

NEXT STEPS

- Complete the initial and follow-up audits of anti-psychotic prescribing in primary care; analyse the data.
- Support GP practices with review and withdrawal according to clinical guidelines.
- Use audit tool as basis for Leeds 'protocol'.
- Produce information for people with dementia, families and community groups, to raise awareness of what to look out for and what to do.
- Dementia needs analysis to include the availability and use of psycho-social support with behavioural and psychological symptoms of dementia.



14 Living well with dementia 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)

- 14.1 About one-third of people with dementia live in care homes; and about two-thirds of people living in care homes have dementia. Supporting someone with dementia to live in one's own home can become very difficult, and when a family carer can't get a good night's sleep, or is having to manage continence difficulties, or unsafe and unpredictable behaviour, a move to a care home is often the outcome. The decision to do so, the process of demonstrating eligibility, searching for a good care home and the administration involved, can be extremely difficult for people with dementia and family members.
- 14.2 Local authorities have generally succeeded in recent years at achieving reductions in care home placements, against the rising demographic trend. This leads to care homes increasingly looking after a cohort of older people with higher care needs, including dementia. The inseparable link between residential care and dementia care is likely to strengthen further.
- 14.3 There are over 80 care homes for older people in Leeds with almost 3,000 staff making up the workforce. Of these, over 20% had started working for that employer in the past year. The great majority of care homes without nursing (residential care), and all care homes with nursing home, are provided by private sector companies, alongside some non-for-profit housing associations and smaller voluntary organisations. Some care homes specialise in dementia as the pre-dominant reason for needing care; but even homes which care for older people with primarily physical needs, must still be able to cater for needs related to dementia.
- 14.4 The local market includes a mix of small local businesses, companies with a regional market, and the large national providers. The local authority has closed some of its own residential homes recently and more are being considered for closure, with the aim of withdrawing from the long-term residential care market. Pressure on local authority finances over recent years has led to the fees paid to care homes, for local authority-funded residents, becoming static or reduced.
- 14.5 There has been much publicity about standards of care and the role of the national regulator, the Care Quality Commission (CQC). Local authorities complement the role of the CQC by managing contracts with care homes; locally, Leeds City Council is leading to develop a new service specification and quality standards, including standards for dementia care based on those in the Department of Health's Dementia Commissioning Pack.
- 14.6 The Leeds Care Association (LCA) represents many independent sector providers, both care homes and domiciliary care. They are represented on the Leeds Integrated Dementia Board and its 'task groups', and currently auditing the training and skills of the workforce employed by their members. This is a positive start, but reaching the care home workforce, with its geographical spread, and range of employers is a significant challenge.

- 14.7 Leeds and York Partnership Foundation Trust (LYPFT) provide a care homes team, to support care homes to understand and manage behaviour associated with dementia and other mental health needs. Anecdotal information is that this team provides valuable support, including where there are associated safeguarding issues, but is unable to offer a quick and flexible response to demand. This will be further examined using data from our dementia needs assessment.
- 14.8 There might be opportunities for admission to a care home to be regarded as temporary, even if this can last for several months. Aggressive behaviour or disturbed sleep, which can be extremely hard for families to manage at home, may subside over time, or strategies developed to reduce it. Short-term admissions to care homes for 'intermediate care' to recover from physical injury and illness are typically 4-6 weeks, but people with dementia may require a more sustained and patient approach. For people with dementia, it may be possible to consider admission to care homes, without ruling out a return home.
- 14.9 The creative and therapeutic approaches discussed above in section 12, are very much relevant to care homes. Investing staff time in planned activities, may reduce the time spent responding to distress and aggression.

The benefits and aims of working with care homes to improve quality:

- A better experience of care and quality of life for people with dementia.
- Better management of behavioural and psychological symptoms, and reduced use of anti-psychotic medication.

NEXT STEPS

- Work with the Leeds Care Association to audit and support workforce development.



15 Good care for people admitted to general 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)

- 15.1. People with dementia probably take up 25% of hospital beds at any one time, across a range of medical specialisms. Often this may not be known and diagnosed prior to hospital admission.
- 15.2. People with dementia are at risk of having to stay longer in hospital than others admitted with the same physical health problem or injury. However, in Leeds, the evidence indicates that services are in place to address this concern. Significant improvements were achieved by the change programme for older people's mental health, which ran from 2006-10 with Department of Health 'POPPs' funding (Partnerships for Older People Projects). This invested in a liaison psychiatry team for older people, to support hospital staff to meet mental health needs; and services to promote safe discharge from hospital. Over this time, detection of dementia improved by 57% and lengths of stay for people with dementia were reduced by 30%.
- 15.3. However, people with dementia do remain at risk of poorer health and poorer outcomes from treatment and require staff to be skilled at assessing and treating both dementia and the co-morbid conditions. Local data suggests that the main reasons for people with dementia being admitted to hospital are fractures, collapse, urinary tract infections, and chest infections.
- 15.4. Hospitals are now incentivised to detect dementia in older people aged 75+. This is known as the 'dementia CQUIN' (which stands for commissioning for quality and innovation). It involves a single 'Stage 1' screening question; if this indicates possible dementia, a more in-depth 'stage 2' assessment; and if indicated, referring for memory clinic services. It applies to people aged 75 and over, admitted on an emergency basis; although in future years it may cover people age 65+ and people admitted for planned treatment, outpatients and day surgery.
- 15.5. In Leeds, the initial screening question is now part of the hospital's standard nursing assessment tool, and will therefore be asked for all admissions. The question is: Has the person been more forgetful in the last 12 months to the extent that it has significantly affected their daily life? The stage 2 assessment has been agreed and is being introduced. The NHS in Leeds, to ensure consistency, has also set up a local CQUIN arrangement for rehabilitation beds run by Leeds Community Healthcare NHS Trust.
- 15.6. The risk of using a CQUIN to change practice is if the financial incentive can be achieved separately to good outcomes for people. We will monitor its implementation, including the impact of increased referrals on memory services. The local pathway must achieve the right treatment for people who:

- are under the age of 75 with dementia;
- have short-term delirium on admission;
- give negative response to the screening question , but there is other evidence for the possibility of dementia;
- are already in the later stages of dementia.

15.7. Leeds Teaching Hospital Trust has set dementia care as one of its top priorities for improvement, and is recruiting to a new post of lead nurse for dementia, and plans to set up a 'shared care' ward, to ensure people with more severe dementia benefit from a staff team combining specialist knowledge of dementia and physical health care. The trust is working with the WRVS and its volunteers to improve quality and dignity in care on the ward.

Benefits and aims of working with hospital trust to improve care for people with dementia:

- Better experience and treatment outcomes.
- Meeting the NICE quality standard.
- Better plans for returning home from hospital.

NEXT STEPS

- Monitor the impact of the dementia CQUIN.
- Leeds Teaching Hospitals Trust to implement plans to improve dementia care, including lead nurse for dementia.
- Use information from the CQUIN to better understand reasons for admissions to acute care.



16 Specialist in-patient care

Admission to an inpatient unit should have a clear objective that is shared from the outset with the person with dementia, the carer and the multidisciplinary team. When the objective has been achieved, there should be an efficient discharge process, supported by community resources.

NICE Clinical Guideline

- 16.1 Leeds and York Partnership Foundation Trust (LYPFT) provide in-patient care for older people needing specialist in-patient mental health care, at The Mount and Asket Croft. The bed-base for this specialist care has reduced, because investment in community services has increased, and succeeded in maintaining more people at home.
- 16.2 This in-patient service is 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. It includes people who have been detained compulsorily under mental health legislation. People leaving hospital following compulsory admission for treatment, are entitled to mental health 'after-care' provision, known as 'section 117', which is free of charge. In Leeds there is an aftercare support service from Age UK.
- 16.3 People at these later stages of dementia are likely to have high incidence of physical health and care needs; the NICE guideline recommends co-location / prompt access to general hospital; dual-trained staff and full multi-disciplinary input. Plans for a 'shared care' ward within Leeds Teaching Hospitals Trust (LHT) are in accordance with this guidance.
- 16.4 Lengths of stay and difficulties with achieving a timely discharge from in-patient beds is a difficulty reported by LYPFT managers. Social care assessment and action to discharge people from specialist beds is not incentivised in the same way as discharge from acute (general) hospitals; and there may be difficulties with finding suitable care home placements, housing options and support.
- 16.5 This specialist service, and other LYPFT provisions, are centres of expertise in dementia care, and there might be innovative ways to share this across the workforce, including family carers.

Benefits and aims of working with in-patient services:

- Supporting timely and good discharge from in-patient wards.
- Improving the quality of experience for people requiring inpatient admission, who are among those with the most severe symptoms of dementia.

NEXT STEPS

- Consider role of ward staff to share expertise with other staff teams.
- Dementia needs analysis to include issues delaying hospital discharge from specialist wards.

17 Dying matters – planning and support for a ‘good death’

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

- 17.1 Dying with or from dementia is the experience of perhaps 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.
- 17.2 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.
- 17.3 The incidence of physical symptoms and needs in the late stages of the condition, means that the majority of people will be in a care home or in hospital. This may be the choice of the person and family, and is entirely appropriate e.g. when a care home has been the person’s home for some time. However, unplanned admissions very near to end of life are not ideal, and can often be prevented by community services.
- 17.4 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.
- 17.5 End of life care for people with dementia, in common with the rest of the dementia journey, is best achieved by health and care services being accessible for people with dementia. Therefore it is to be welcomed that 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.

17.6 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.

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

NEXT STEPS

- Complete local advice for clinicians on recognising and treating pain, and other end-of-life symptoms, with people with dementia.

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 www.direct.gov.uk/en/Governmentcitizensandrights/Mentalcapacityandthelaw/Makingarrangementsincaseyoulosementalcapacity/index.htm
- 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

- You Are Just Left Alone – article from BBC News website, 27th Feb 2007 <http://news.bbc.co.uk/1/hi/health/6391137.stm>
- Perspectives On Ageing With Dementia – Joseph Rowntree Foundation (2012) www.jrf.org.uk/sites/files/jrf/ageing-and-dementia-summary.pdf
- Dementia 2012 – a national challenge. Alzheimer's Society (2012) http://alzheimers.org.uk/site/scripts/download_info.php?downloadID=821
- Interview with Barbara Pointon, The Guardian (2007) www.guardian.co.uk/society/2007/dec/12/dementiacare
- The rhyme and reason of reading to dementia patients. www.guardian.co.uk/society/2010/oct/05/reading-aloud-dementia-patients
- Counting the cost: caring for people with dementia on hospital wards. Alzheimer's Society (2009). http://alzheimers.org.uk/site/scripts/download_info.php?fileID=787

National documents

- National Dementia Strategy (2009) www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058
- 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

Evidence

- Dementia UK (Alzheimer's Society, 2007) www.psige.org/psige-pdfs/Dementia_UK_Summary.pdf
- 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 (local Leeds 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](http://www.rcpsych.ac.uk/pdf/JCP-MH%20dementia%20(March%202012).pdf)

