



DRAFT

V2.4

Lincolnshire Joint Commissioning
Strategy for Dementia Care
2014 - 2017 : The Way Forward



Document Control

Document purpose: A commissioning strategy for services for adults with dementia in Lincolnshire. Endorsed by the Joint Commissioning Board for Lincolnshire, and the Lincolnshire Health and Wellbeing Board.

Title: Lincolnshire Joint Commissioning Strategy for Dementia Care 2014 -2017:
The Way Forward

Author: Paul Herniman

Publication date: TBC

Review date: TBC

Target audience: Lincolnshire County Council: Adult Care, Public Health; Lincolnshire West Clinical Commissioning Group, South-West Lincolnshire Clinical Commissioning Group, Lincolnshire East Clinical Commissioning Group; South Lincolnshire Clinical Commissioning Group, United Lincolnshire NHS Hospitals Trust, Lincolnshire Partnership NHS Trust, Lincolnshire Community Health Services NHS Trust, Third Sector organisations, district councils, housing associations, Job Centre Plus, Lincolnshire Police, carers, people with dementia, all contributors, residents of Lincolnshire.

Action required: secure funding, develop business plans, develop work plans, monitor and report developments.

Version : **2.4 DRAFT**

This document is available in alternative formats on request.

Contents

1. Making the Case for Change	4
2. Executive Summary	5
3. The National Context	5
4. The Local Context: what is the picture in Lincolnshire?	7
5. The Priorities: what are Lincolnshire people telling us now?	14
6. An Improved Dementia Journey for Lincolnshire	15
1. Seeking help	15
2. Getting a diagnosis	16
3. Finding out more	17
4. The right help at the right time	19
5. Managing at more difficult times	20
6. Inpatient Care	21
7. End of Life	22
7. Our vision for 2014 – 2017	24
8. Governance: who will be responsible for ensuring the strategy is delivered?	24
	25
9. Appendix A: Action Plan	

1. Making the Case for Change

Dementia is one of the most important issues we face as the population ages. Local authorities, the NHS and the community as a whole must respond to this challenge; Lincolnshire is no exception.

The term dementia describes a set of symptoms that include loss of memory, mood changes, and problems with communication and reasoning. There are many types of dementia of which the most common are Alzheimer's disease and vascular dementia. Although dementia is primarily a condition associated with older people, there are also a significant number of people who develop dementia earlier in life.

The Prime Minister said:

"One of the greatest challenges of our time is what I'd call the quiet crisis, one that steals lives and tears at the hearts of families, but that relative to its impact is hardly acknowledged.

We've got to treat this like the national crisis it is. We need an all-out fight-back against this disease; one that cuts across society."

Prime Minister David Cameron, speaking at the Alzheimer's Society Conference, March 2012

Dementia is one of the most severe and devastating illnesses we can face. It is a terminal illness, but people can live for 7–12 years after diagnosis. It is also very common.

In Lincolnshire estimates show there were approximately 10,300 people with dementia in 2011. This number is predicted to grow to over 17,800 in 2023. In most district council areas this represents a doubling of cases within 15 years.

Dementia can affect anyone in society irrespective of gender, ethnicity, education or class. Adults of working age are affected as well as older adults, and people with learning disabilities are particularly at risk.

Besides the devastating impact on those with the illness, dementia can also have a profound and negative effect on family members who, in many cases, provide the majority of care. However, dementia is not an inevitable consequence of ageing and, contrary to what some people believe, a great deal can be done to help and support people with dementia.

This strategy has been developed jointly by Lincolnshire County Council and NHS Clinical Commissioning Groups working closely with local partners, stakeholders, carers and people who use social care and NHS services.

(Signed on behalf of Adult Care)

(Signed on behalf of CCGs)

2. Executive Summary

Dementia is one of the most pressing challenges for health and social care services both nationally and locally.

It is estimated that currently there are over 750,000 people in the United Kingdom living with dementia with this figure likely to rise to one million by 2021 in the absence of any medical breakthrough in treatment.

The National Dementia Strategy has identified 17 key objectives which when implemented will result in significant improvements in the quality of services provided to people with dementia and should promote a greater understanding of the causes and consequences of dementia.

Besides the impact on those who develop dementia, the condition can also have a profound and negative effect on family members who, in many cases, provide the major share of care and support.

This strategy for 2014 – 2017 has been developed jointly by Lincolnshire County Council and NHS Clinical Commissioning Groups working closely with local partners, stakeholders, carers and people who use social care and NHS services. The document supersedes the Lincolnshire Joint Commissioning Strategy for Dementia Care 2010 -2014.

Lincolnshire's strategy complements the National Dementia Strategy which sets four priority areas:

- Good quality early diagnosis and intervention
- Improved quality of care in general hospitals
- Living well with dementia in care homes
- Reduced use of antipsychotic medication

More generally the improvement of community personal support services is integral to and underpins each of the four priorities as it supports early intervention;

The physical health care needs of people with dementia, particularly in relation to acute general hospital care has been examined in NHS England's report of 2013 which includes the following aims :

- Improve the health related quality of life of the 15 million+ people with one or more long-term conditions;
- Reduce the amount of time people spend avoidably in hospital through better and more integrated care in the community, outside of hospital;
- Increase the proportion of older people living independently at home following discharge from hospital;
- Reduce the proportion of people reporting a very poor experience of inpatient care;

It is estimated that only around 45% of people living with dementia are diagnosed and registered. Having regard to this, the national incidence rates have been used to estimate dementia prevalence and future projections.

In Lincolnshire the number of people over 65 with dementia has been estimated at 10,460 for 2012, rising to 11,843 by 2016 and 13,589 by 2020.

Since publication of The Lincolnshire Dementia Care Strategy 2010 – 2014 significant progress has been made but areas of improvement remain.

Specifying how much is spent specifically on dementia services is difficult to quantify because services are generally commissioned to meet needs rather than address a particular medical diagnosis. The bulk of spending relevant to dementia is contained in older peoples' services.

A countywide consultation held in May and July 2013 was designed to give as many people, groups and organisations the opportunity to give their views and experiences of dementia services, as a way of charting progress to date, and outlining proposals for further progress.

The consultation confirmed a number of widely supported conclusions :

- The need for services to be better integrated, both between health care and social care in general as well as between community and hospital based services.
- The need for better information and guidance on dementia and more effective ways of ensuring information is available at the right time to the right person.
- Carers feel their needs are not adequately recognised and that services are not always available when needed or delivered in the most acceptable way.
- Carers cannot always find adequate financial advice. This applies particularly to people self-funding their social support.
- Access to respite care suitable for people with dementia is difficult in many localities. Carers also say there is no suitable brokerage service to determine what options are available

People affected by dementia need to know what support is available, when they can expect it to be available, and who will provide it. Our aim is to develop a range of options at each stage of the dementia journey to enable families to access the help they need when they need it, and to know what is likely to be available in the future when their circumstances change.

The Lincolnshire Joint Commissioning Strategy for Dementia Care has been developed in partnership with a wide range of individuals and organisations, using a variety of methods to identify the key priorities. An action plan is appended to this document and is based on realistic expectations of what needs to be achieved to

meet the reasonable expectations of Lincolnshire people over the period 2014 – 2017.

The joint Dementia Core Group, and the Health and Wellbeing Board for Lincolnshire will be responsible for agreeing and insuring implementation of all aspects of this Strategy and associated plans.

Partner agencies will set up a Joint Dementia Programme Board to co-ordinate all activity across health and social care.

3. The National Context

There are estimated to be over 750,000 people in the UK with Dementia.

- The number with dementia nationally is expected to double in 30 years to 1.4 million.
- There are 13,000 people nationally who have developed dementia earlier in life.
- 50% of people with Down's Syndrome aged 60-69 and 22% of those over 60 with other learning disabilities are recognised to be at risk of dementia.
- 59 % of dementia patients had two or more concurrent illnesses or diseases.
- 40% of people admitted to hospital have dementia.
- 50% of people who have a hip fracture have dementia.
- Over a third of people with dementia (244,000 nationally) live in care homes and two thirds at home.
- At least two thirds of care home residents in the UK have dementia.
- 45% of care home residents have moderately severe to very severe cognitive impairment (Alzheimer's Society)
- Direct costs of dementia to the NHS and Social Care are in the region of £8.2bn a year nationally.
- The report *Dementia does not discriminate*' (July 2013) by The All-Party Parliamentary Group states that nationally there are nearly 25,000 people with dementia in ethnic (BAME) communities.
- Patients with dementia admitted to hospital have higher mortality rates, longer lengths of stay and are more susceptible to complications such as delirium and hospital acquired infection. They are also more likely to be transferred to institutional care than their counterparts without dementia.

Key national initiatives to address the challenge of dementia have included:

'Living well with Dementia – A National Dementia Strategy' was published in February 2009. It set out a vision for transforming dementia services with the aim of achieving better awareness of dementia, early diagnosis and high quality treatment at whatever stage of the illness and in whatever setting. The Strategy was followed in November 2009 by the publication of a report addressing the over-prescription of antipsychotic medication for people with dementia. Implementation of the 11 recommendations contained within that report is an integral part of improving the care and experience of people with dementia and their carers.

In 2010/11 the Department of Health's set four priority areas to support local delivery of the Strategy. These areas provided a focus on activities that are likely to have the greatest impact on improving quality outcomes for people with dementia and their carers. It is important to emphasise however that the priorities are enablers for local delivery of the Strategy in full, as well as the work to implement the recommendations of the report in to the over-prescribing of antipsychotic medicines to people with dementia.

The four priority areas are:

Good quality early diagnosis and intervention for all - Two thirds of people with dementia never receive a diagnosis; the UK is in the bottom third of countries in Europe for diagnosis and treatment of people with dementia; only a third of GPs feel they have adequate training in diagnosis of dementia.

Improved quality of care in general hospitals - 40% of people in hospital have dementia; the excess cost is estimated to be £6m per annum in the average General Hospital; co-morbidity with general medical conditions is high, people with dementia stay longer in hospital.

Living well with dementia in care homes - Two thirds of people in care homes have dementia; dependency is increasing; over half are poorly occupied; behavioural disturbances are highly prevalent and are often treated with antipsychotic drugs.

Reduced use of antipsychotic medication - There are an estimated 180,000 people with dementia on antipsychotic drugs. In only about one third of these cases are the drugs having a beneficial effect and there are 1800 excess deaths per year as a result of their prescription.

More generally the **improvement of community personal support services** is integral to and underpins each of the four priorities as it supports early intervention; prevents premature admission to care homes and impacts on inappropriate admission to hospital and length of stay.

The *Prime Minister's Challenge on Dementia* launched in March 2012 sets out plans to go further and faster in improving dementia care, focusing on raising diagnosis rates and improving the skills and awareness needed to support people with dementia - and their carers. It also has details of plans to improve dementia research.

Health and social care partners in Lincolnshire continue to focus on the *Prime Minister's Challenge* by addressing:

1. Creating dementia friendly communities
2. Driving improvements in health and care
3. Delivering the National Carers' Strategy for dementia carers

Acute hospital care for people with Dementia

The physical health care needs of people with dementia, particularly in relation to acute general hospital care has been scrutinised through the Royal College of Physicians' report '*Who Cares Wins*' (1995) and the Alzheimer's Society's 2010 paper '*Counting the Cost*'.

Key themes from these papers are:

- The requirement for improved training for all hospital staff in dementia care.
- The need for expert liaison and dementia champions.
- The need for better outcomes regarding prescribing of anti-psychotics, length of hospital stay, access to rehabilitation, pain management, ward moves contributing to disorientation and undermining continuity of care, and increased dependency leading to long term care.

More recently in NHS England's Planning for a sustainable NHS 'call to action' October 2013 there is a drive to

- Improve the health related quality of life of the 15 million+ people with one or more long-term conditions;
- Reduce the amount of time people spend avoidably in hospital through better and more integrated care in the community, outside of hospital;
- Increase the proportion of older people living independently at home following discharge from hospital;
- Reduce the proportion of people reporting a very poor experience of inpatient care;
- Reduce the proportion of people reporting a very poor experience of primary care;
- Make significant progress towards eliminating avoidable death in our hospitals.

4. The Local Context: what is the picture in Lincolnshire?

Lincolnshire is the fourth largest county in the UK, with a total area of almost 6000 square kilometres. It has a predominantly rural based population of over 700,000. The county has a mix of some large conurbations, sparsely populated rural areas and coastal communities that have an inward retirement migration.

Increasing older population

The increase in the older population varies across the County; however each district is predicted to see an increase. The majority of older people will lead full, active and healthy lives, playing a part in their communities, enjoying sport, leisure and cultural activities. However, there is an increasing number living longer which will also mean increased frailty and dependence, and poorer health.

Around 21% of the population are aged 65 or over. The figure for England is 16%. Current population projections of over 65s show:

Table 1: population projection

	2010	2015	2020	2015
Lincolnshire	150,400	179,200	201,900	226,900

Source: POPPI. Population aged over 65 projected to 2025.

Nationally, it is estimated that only around 40% - 50% of people living with dementia are diagnosed and registered. Having regard to this, the national rates established by Alzheimer's Society in 2007 have been used to estimate dementia prevalence and future projections in Lincolnshire.

The National Dementia Prevalence Rates (NDPR) expressed as a percentage of each age group show:

Table 2 : prevalence rates

	65-69	70-74	75-79	80-84	85-89	90+
Males	1.5%	3.1%	5.1%	10.2%	16.7%	27.9%
Females	1.0%	2.4%	6.5%	13.3%	22.2%	30.7%

Source: Alzheimer Society, Dementia UK, 2007

The table above only takes into account rates for later onset of dementia (ages 65+). Rates are also available for people aged below 65 and those vary from 0.01% for the age group 30-34 to 0.2% for 60-64.

Applying the above rates to the total population in each of the age and gender groups, using this estimate, the number of dementia cases across Lincolnshire in 2011 was over 10,300 people and is projected to rise as shown below :

Table 3 : Total population of Lincolnshire over 65 predicted to have dementia

	2012	2014	2016	2018	2020
People 65+ predicted to have dementia	10,460	11,170	11,843	12,690	13,589

Source: Projecting Older People Population System (2013)

Diagnosis rates

Diagnosis rates in Lincolnshire are broadly in line with national figures. The number of people diagnosed with dementia in 2012/13 and included in the Quality Outcomes Framework ("QOF") register are shown by CCG in Table 4.

Table 4 : numbers of patients on dementia register

CCG	QOF Registers 2012/13	% of Predicted Cases
Lincolnshire East	1843	46.66%
Lincolnshire West	1488	46.47%
South Lincolnshire	1048	46.03%
South West Lincolnshire	811	47.59%

Source : Clinical Commissioning Groups

The figures confirm actual numbers as a percentage of the predicted number. Table 5 gives the proposed number of diagnoses, year on year, that CCGs aim to achieve to increase overall numbers registered.

CCG	2012 / 13 (Actual)	2013 / 14	2014 / 15	2015 / 16
Lincolnshire East	299	331	294	305
Lincolnshire West	92	274	239	247
South Lincolnshire	36	205	170	176
South West Lincolnshire	40	127	127	131

Source : Clinical Commissioning Groups

Early onset dementia

An estimated 200 people in Lincolnshire are affected by dementia before reaching age 65. (Source: PANSI, 2012). Whilst the number of people under the age of 65 with dementia is relatively small, it is important to recognise that existing services, designed primarily for older adults are not always appropriate to meet the needs of this group. Feedback frequently states that people of working age affected by dementia require greater flexibility in service provision and more choice, as well as support services which address issues of employment, financial planning, and relationships.

Spending on services

The NHS and Adult Care both invest significant sums into services for older people; in 2012/13 adult social care services were supported by a net budget of £133.9m.

Unpicking the sums specifically for dementia services is difficult and likely to be misleading, as services have been commissioned to meet a person's need not according to medical diagnosis. Commissioning new services will focus on enabling people with dementia to be able to access mainstream services wherever possible.

Dementia Strategy 2010 - 2014

The Lincolnshire Dementia Care Strategy 2010 - 2014 was jointly developed by health and social care commissioners and providers. An extensive consultation process involved patients, service users and carers and supporting agencies. A series of consultation events were held across the county to map current service provision and to identify what new services and support people felt were needed. People were able to share their experiences of living with the condition or of caring for or supporting someone with dementia.

What did people say?

This diagram was designed by people with dementia and their carers in Lincolnshire. The diagram illustrates areas of care and support people felt were most important to them.



Progress since 2010: what has been done so far?

Since publication of the strategy in 2010 Lincolnshire has made progress in a number of areas:

1. Telecare and Telehealth facilities for people with dementia are more widely available although more work is needed to make sure people understand how they could benefit from the services. Follow link for details : www.lincstelecare.co.uk
2. Development of carers' courses addressing, among others, emotional support, practical strategies for living with dementia, moving and handling, postural care, dementia awareness and communicating with a person with dementia.
3. Carers affected by dementia can request an assessment of their needs and access continuing support from Lincolnshire County Council Carers' Team and Carers Connect. Ongoing help includes support groups, assistance with benefits, carers' education and dementia awareness.
4. New Extra Care housing schemes which accommodate the needs of people with dementia.
5. Lincolnshire County Council's online information and advice service www.MyChoiceMyCare.org.uk has a new dementia section.
6. A pilot scheme to support care homes in the Boston area has been led by United Lincolnshire Hospitals Trust as part of their initiative to promote good end of life care. Their aim is to promote best practice in care co-ordination between hospital and care homes and avoid futile and burdensome admissions at the very end of life.
7. A new service provided by the Alzheimer's Society will help patients and carers affected by dementia at Pilgrim Hospital, Boston, by providing support and guidance. Subject to successful evaluation of the scheme, it is hoped that the service can secure funding to be extended to hospitals at Lincoln and Grantham.
8. Workforce development plans are in progress. A number of training initiatives have helped NHS and social care staff, care providers and care home staff in the independent sector to become better skilled in working with people with dementia. Initiatives by the Workforce Quality and Development Team have included:
 - Work to help support managers in their development of a high quality dementia workforce that is confident and competent in the workplace.
 - 'Making a Difference in Dementia Care' is a 2 & 1/2 day (care home) & 1 day (Home care and community based services) taught course commissioning Senior Moments alongside a sector professional which is aimed at managers or those who influence training within a care setting.

- 'Quality of Interactions Schedule' (QUIS) is a 2 day taught course commissioning an independent trainer and aimed at introducing observations that in turn will encourage and develop a more Person Centred Approach by the workforce with people who have dementia. The development of this QUIS approach in Lincolnshire has led to an article being written in a national journal and thus being showcased at the Dementia conference in Brighton in November 2012.
- 'Train the Trainer', a three day taught course delivered by the Alzheimer's Society, February, March and April 2013. Delegates accredited as Alzheimer's Society Cascade Facilitators which enables them to cascade the "Train the Trainer" pack to providers in the independent residential and domiciliary care sectors.
- Activities Co-ordinator training has been provided over three days by an independent trainer to providers in the residential and day care sectors.
- A conference on dementia training aimed at managers and people who are able to influence and motivate their workforce was held in February 2013.

9. A further funding stream for memory services has allowed the commissioning of a comprehensive information and awareness service for 2013 -2015 provided by the Alzheimer's Society in all districts of Lincolnshire starting from April 2013. Mobile libraries will be used to distribute information to a range of smaller communities. A number of medical practices have agreed to be information sites, and to host information events. Other elements of the plan include: a dementia page for Lincolnshire on Facebook, and co-ordinating linking with hospital discharge teams, Age UK, LPFT, local surgeries, First Contact, and CCG websites. General information and advice continue to be available on the national Alzheimer's Society website.

10. Prescribing rates for anti-psychotic medication in patients newly diagnosed with dementia have reduced from 5.4% in 2006 to 0.7% in 2011.

11. Support for the Dementia Action Alliance (DAA) initiative: Lincolnshire County Council and Lincolnshire Partnership NHS Foundation Trust are members of both the Lincoln DAA group and the South Lincolnshire DAA group.

Part of a national initiative, the Dementia Action Alliance is a network of organisations from across the charity, public and private sectors to radically improve the lives of people with dementia. Members subscribe to the National Dementia Declaration, which is a set of seven outcomes developed by people with dementia and their family carers with support from initial signatories:

- 1. I have personal choice and control or influence over decisions about me*
- 2. I know that services are designed around me and my needs*
- 3. I have support that helps me live my life*
- 4. I have the knowledge and know-how to get what I need*

5. *I live in an enabling and supportive environment where I feel valued and understood*
6. *I have a sense of belonging and of being a valued part of family, community and civic life*
7. *I know there is research going on which delivers a better life for me now and hope for the future*

Separate to this Declaration, each signatory organisation sets out what it plans to do by 2014 (the date when the current National Dementia Strategy comes to an end) in order to deliver better quality of life for people living with dementia and their carers.

The South Lincolnshire Dementia Action Alliance was officially launched on 23 October 2012. The group includes members in the south of Lincolnshire.

The Lincoln Dementia Action Alliance was launched on 1 October 2012. This group includes members from the Lincoln area.

Both groups have attracted an encouraging level of support including from EMAS, Lincolnshire Police, the City of Lincoln Council, the Alzheimer's Society, LACE and other Third Sector groups and agencies.

12. Lincolnshire Partnership NHS Foundation Trust have arranged a programme of events throughout the county to raise awareness of dementia. Such events are listed on the LPFT website.

13. The Transparency in Dementia Information Project, a national initiative, was prompted by The Prime Minister's Dementia Challenge and based on the work of the NHS South West 'Our Health' website which offers a comprehensive overview of dementia and stroke services. The aim has been to make the best use of information available at local, regional and national levels, so that people with dementia and their families, before and after diagnosis, and local voluntary agencies, can access what is available more effectively and quickly. Lincolnshire submitted information in December 2012 regarding the current status and future plans for the provision of information, advice and guidance. As part of this commitment, the website *MyCareMyChoice* has included information and advice relevant to, as well as specifically for, people affected by dementia.

Public Health

1. The delivery of public health outcomes in dementia care is led by the county wide Excellent Ageing Partnership, which is a delivery group of the Health and Wellbeing Board. Improving the understanding of the general public on dementia and enhancing the quality of life of people with dementia are priorities within the Lincolnshire Joint Health and Wellbeing Strategy 2013-17. Lincolnshire County Council Public Health will continue to contribute to the county's Dementia Care Strategy in the following ways:

- Contribute to the local public awareness raising campaign on dementia by enabling:
 - a) Community pharmacies to run a targeted campaign on Dementia Awareness in March 2014. This will include awareness and signposting for pharmacy staff.
 - b) The list of books that GPs and nurses can prescribe to patients and carers will be expanded to increase the number of titles about dementia. These will include easy read versions for people with Learning Disabilities.
 - c) Promotion of dementia and memory problems, and the availability of support services in the countywide '*Good Life Guide*' publication.
- Promote the Dementia Action Alliance '*Dementia Friends*' and '*Dementia Champions*' initiatives with Public Health staff and partners by including specific dementia awareness expectations in relevant new contracts and grants.
- Promote Dementia Friendly Environments alongside Lincolnshire County Council Spatial Planning Teams to explore the development of specific reference to dementia friendly environments in the '*Every Street Matters*' local guidance. Exploring with Excellent Ageing partners such as district councils and private sector organisations the development of dementia friendly environments as part of Age Friendly Communities initiatives.
- Provide active engagement and support to the Lincolnshire Carers and Young Carers Partnership, Senior Forums, Healthwatch and locality dementia care groups so they can influence, feedback and share their experiences of dementia care services to inform the Health and Wellbeing Board's future decision making.
- Public Health teams currently provide a range of services which facilitate healthy lifestyles to reduce obesity, excessive alcohol consumption, smoking, high blood pressure, high cholesterol. Evidence is increasingly clear that these interventions and changes will affect dementia prevalence. Teams will explore how existing programmes will promote more inclusive or tailored support to people affected by dementia such as Healthy Walks or Vitality Classes.
- Depression can be an early manifestation of dementia and there are increased rates of depression in people diagnosed with dementia. Public Health continues to support several mental health initiatives such as the Shine Network to support wider emotional and mental health needs associated with dementia. These outcomes will be monitored through the Lincolnshire Mental Health Strategy.

Funding: how much is spent on dementia services?

Specifying how much is spent specifically on dementia services is difficult to quantify because services are generally commissioned to meet needs rather than address a particular medical diagnosis. The bulk of spending relevant to dementia is contained in older peoples' services although small elements of expenditure may be met from other budget headings such as Mental Health and Intermediate Care. The older peoples' budget heading includes such items as Direct Payments, day care, home support, respite care, and long term care.

In 2009/2010 spending by the NHS and Adult Social Care in Lincolnshire on older peoples' services was £16m and £95m respectively.

In 2012/13 actual spend by Adult Social Care had increased to £109.1 m. The budget for 2013/14 is currently set at £109.6

By comparison with other regional comparator authorities, Lincolnshire spends the least on adult social care services, which includes older peoples' services. A Lincolnshire County Council internal report showing total adult social care expenditure for 2011/12 confirms a total spend of £201m for Lincolnshire compared with £286m for the next highest spending authority, Leicestershire. Derbyshire and Nottinghamshire spent £330m and £364m respectively. Expenditure per capita, however, shows a figure of £282 per head for both Lincolnshire and Leicestershire; Derbyshire and Nottinghamshire show per capita spending at £335 and £334 respectively.

Personal Health Budgets will become relevant to increasing numbers of people with longer term health care needs, including people with dementia.

A personal health budget is an amount of money to support a person's identified health and wellbeing needs, planned and agreed between the person and their local NHS team. Our vision is to enable people with long term conditions and disabilities to have greater choice, flexibility and control over the healthcare and support they receive. Personal Health Budgets are being rolled out across the NHS nationally. When introduced in Lincolnshire, Personal Health Budgets will initially be aimed at people who get NHS Continuing Healthcare funding.

A "right to ask" for a Personal Health Budget for this group of patients will become effective from April 2014, and will be extended to a "right to have" from October 2014.

Those already on NHS Continuing Healthcare will be able to continue to access the services they are familiar with as they will be in control of how their budget is spent and have the confidence to exercise choice. Similarly, those who are new to NHS CHC, those who transition in from social care budgets or those who transition from children's services will be able to continue to access the services they are

accustomed to without the fear that this power to choose will be taken away from them when they move to a new package of care.

5. The Priorities: what are Lincolnshire people telling us now?

The current strategy has been in place since 2010 and many people and organisations have been working creatively in a difficult economic climate to deliver changes over this period. It is important to be able to evaluate progress and for everyone to be able to share and understand what we have achieved to date.

The consultation held in May and July 2013 was designed to give as many people, groups and organisations the opportunity to give their views and experiences of dementia services, as a way of charting progress to date.

Ideas from the original strategy that still needs action or can no longer be delivered or be delivered in a different way. The aim of this engagement exercise is to co-produce a new strategy and action plan with as many individuals and organisations as possible who feel they can offer support and change in dementia care.

What has the consultation said?

A comprehensive Consultation Evaluation Report accompanies this strategy document. The main themes identified by the individuals and groups which participated are summarised here:

- The need for services to be better integrated, both between health care and social care in general as well as between community and hospital based services.
- The need for better information and guidance on dementia and more effective ways of ensuring information is available at the right time to the right person.
- Carers feel their needs are not adequately recognised and that services are not always available when needed or delivered in the most acceptable way.
- Carers cannot always find adequate financial advice. This applies particularly to people self-funding their social support, and to carers receiving financial support
- Access to respite care suitable for people with dementia is difficult in many localities. Where care homes offer short-term respite facilities it is frequently not available on a bookable basis. Carers also say there is no suitable brokerage service to determine what options are available

6. An improved Dementia Journey for Lincolnshire : Introducing the 'Dementia Journey'

The consultation draws on the concept of the “Dementia Journey”, designed by Dementia Partnerships UK the country's leading innovation hub bringing together

people, partnerships and networks to share knowledge and learning to improve the quality of life for people with dementia. The Dementia Journey helps focus thinking on the way dementia affects people at various stages and how support needs vary from stage to stage:



1. Seeking help

Consultation data shows the overwhelming majority of people went initially to their GP for information and help when the first signs of dementia started to appear. Other notable sources of information and help were family and friends, voluntary organisations and the internet.

Of those seeking information and help from voluntary organisations, the majority contacted the Alzheimer's Society. Other organisations mentioned include Age UK and Dementia UK.

Awareness of dementia among the general population remains low and the need for good basic information and advice is fundamental. Most people wanted clear information about what help and services are available preferably through a single reference point.

The key role of Primary Care as a preferred access point for information should be acknowledged. **Social Care and CCGs will work with Primary Care practices to ensure patients and carers can access information and guidance on dementia at their point of contact on a consistent basis.**

Commissioners will also promote and encourage services which provide information on dementia through other channels. Commissioners will continue to support specific projects such as the Alzheimer's Society Awareness and Information Programme.

2. Getting a diagnosis

Most people see GPs as their main point of reference if they have concerns about dementia. The need for early diagnosis was highlighted as a priority by most people. The role of GPs in facilitating referrals to specialist diagnostic and treatment services was generally acknowledged.

When dementia is diagnosed carers want:

- All professionals, but particularly GPs, to listen to and take account of carers concerns.
- Timely diagnosis (including access to diagnostic tests and information about them).
- Access to specialist services for example, in memory clinics, early onset dementia services, regional services for rare dementias).
- Advice and information about dementia-related medication.

Many people were concerned that services are not joined up well enough. Although the consultation gave evidence of good practice in individual cases many carers in particular felt a lack of co-ordination between medical services and particularly between NHS services and social care. Professionals also thought there were unresolved queries about how best to deliver integrated clinical and support services to dementia patients and carers. Clear diagnostic and support pathways need to be agreed to ensure the seamless operation of services.

Lincolnshire will develop and publish a comprehensive pathway for dementia

At the core of the pathway will be a diagnostic and clinical route clearly showing points of interaction with social care services and including elements of self-support, where appropriate, in areas such as information.

The needs of younger people with dementia will be recognised

People diagnosed with dementia under the age of 65 are often described as 'younger people with dementia' by health and social care professionals. Other terms used include 'early onset dementia', 'young-onset dementia', and 'working age dementia'. The symptoms of dementia may be similar regardless of a person's age, but younger people may have different needs, and require different support.

The needs of younger people with dementia and their friends and family are not just related to age. Younger people may have different concerns and interests to older people. A service set up for people of a different generation, where activities are planned for older people who are less physically active, is unlikely to meet the needs of younger people. Younger people with dementia require specialist services, able to meet their complex needs. Specialist services should strive to help people maintain their day-to-day skills, friendships, hobbies and interests, and support people to continue to live an active life as a member of the local community.

These factors will be taken into account when designing diagnostic and care pathways and drawing up service specifications

Early onset dementia may impact on:

- Employment – patients are more likely to be in work at the time of diagnosis
- Dependent children still living at home
- Partner or spouse
- Financial commitments, such as a mortgage
- Awareness – patients are more likely to be aware of their disease in the early stages
- Emotional impact – people find it hard to accept and cope with losing skills at such a young age, and the emotional and physical strain on the family may be severe
- Finding suitable services – information, support and services are likely to be tailored to the needs of older people

The needs of people with Learning Difficulties will be recognised in pathway design. There is now, generally, a better understanding about the particular link between Down's syndrome and dementia; 50% of people with Down's Syndrome aged 60-69 and 22% of those over 60 with other learning disabilities are recognised to be at risk of dementia. As people with Learning Disabilities are increasingly represented in these age groups it is important to ensure that these service users and patients obtain appropriate assessment and treatment from the onset of their condition.

Those working in clinical and social care will be supported to improve the quality of life of people with learning disabilities who develop dementia, by providing appropriate assessment, diagnosis, treatment and support.

3. Finding out more

Consultation responses indicate there are few services between the point of diagnosis and the point at which medical and social care intervention becomes necessary. There is some indication of a reluctance by health and social care staff to encourage diagnosis in the belief that few services would be subsequently available. People affected by dementia are often left feeling unsupported until long term residential care or further medical intervention become necessary.

Carers said there was often a lack of suitable respite care options, both in care homes, and on a domiciliary basis. The need for advice and guidance to navigate clinical and care systems was also highlighted. Practical issues such as finance, benefits, legal queries as well as medical concerns were raised.

Commissioners will develop a Family Support Service to ensure consistent support to carers. This service is proposed to offer holistic support to families with a suspected or diagnosed case of dementia. It will offer information, advice and continuing support to both the individual and the family carer throughout the whole of the dementia journey. Offering a consistent point of contact, this will include one to support, access to counselling, access to carers education and training such as dementia awareness or managing challenging behaviour, access to a carer's assessment, peer support and peer social events and activities, advance care planning and more.

Housing for people with dementia is an area requiring more co-ordinated activity. Commissioners in Lincolnshire will need to plan to meet growing demand for services which provide appropriate support and maintain independence.

The housing sector includes a wide range of housing and related organisations employing staff who design, develop or deliver services to people who may have or develop dementia. In Lincolnshire a range of providers run retirement and sheltered housing schemes, extra care housing, handy person and home improvement agency.

A whole systems approach is needed to achieve the intended outcomes of the dementia strategy. Housing - and third sector generally - provide many early intervention services which support well-being. They could contribute significantly to preventing or delaying the use of more costly, and sometimes disabling, later services. This potential can only be realised if the sector's contribution is embedded into every aspect of the dementia strategy, alongside that of health and social care professionals rather than being treated as an add-on.

A range of services have been provided under housing related support which have helped people who have primarily been tenants of social housing. This did mean that people who lived in privately rented or their own properties did not have equal access to services. The Wellbeing Service is the new model of delivery for helping people to remain independent at home for as long as possible, reducing hospital admissions and the need for long term residential care. The service comprises of an assessment of the support required; installation of small pieces of equipment; minor home adaptations; TeleCare ; including a rapid response service and/or a short term period of generic support to ensure service users feel safe in their own home and engage with community services and/or activities. This new service will be available from April 2014.

Specific areas of collaboration and development include:

- Improving awareness
- Early diagnosis and intervention
- Improving quality of care.
- Supporting independence and control through the Wellbeing Service.
- Increasing the use of Telecare to support people with dementia and their carers to live safely and remain as independent as they are able.
- Providing specialist housing with care for people with dementia
- Working together with health and social care staff to provide coordinated holistic support to individuals
- Supporting a person with dementia's right to continuing and end-of life care at home
- Building effective partnerships between housing, social care and health at a systemic level to improve the co-ordination and effectiveness of care pathways
- Research into housing and dementia – e.g. the effectiveness of different models of housing with care; different building designs for people with dementia – to provide an evidence base
- General needs housing designed to lifetime home standards
- Specialist housing to incorporate specific dementia-friendly design
- Ensuring suitable tenure arrangements in the context of declining mental capacity

The new Wellbeing Service scheduled to start in April 2014 is designed to provide

Delivery of these contributions requires a dementia strategy which is inclusive of sectors, staff and services outside health and social care.

Social care and health care commissioners in Lincolnshire will develop a housing and support strategy to acknowledge the needs of people with dementia.

Only in this way is a coordinated and integrated framework for improving the well-being of people with dementia and their carers likely to be achieved.

4. The right help at the right time

The consultation asked what helped people with dementia and their families to live as well as possible with the condition. People rated as most helpful:

- 1) Support of family and friends
- 2) Support for you as a carer
- 3) Easy to contact knowledgeable help and support
- 4) Home care or other paid support in the home

Lincolnshire will make a strategic shift away from long term high cost maintenance services to investment in earlier intervention and prevention to support people in the community at earlier stages in the dementia journey. Advantages of this approach will include improved outcomes through more services for individuals, more reliable community support, individualised services and more consistent pathways.

Lincolnshire will develop a Dementia Support Network. Health and social care commissioners will submit a bid and outline plans to secure a budget from existing funding streams. Discussions with potential external partners will be pursued to attract additional funding.

Investment will be sought to develop prevention and early intervention services to support people with relatively low levels of need at an early stage with the intention of maintaining community solutions for as long as possible without the need for unnecessary residential care or hospital involvement. Practice in other service areas suggests that a mixture of grant supported and contracted support services can both free up funding from residential services as well as improve outcomes for service users and patients. Mechanisms will be developed to provide funding to support local initiatives, fill gaps in provision and encourage innovative solutions.

Lincolnshire will improve the use of Telecare and Telehealth in supporting people with dementia. Consultation feedback shows a mixed response from patients, carers and professionals concerning the relevance of telecare and telehealth. There is evidence that many people do not have adequate information on this subject despite the range of information on MyChoiceMyCare.

. There are equally suggestions that the potential of telecare and telehealth would be enhanced by better information and awareness among all groups. Significant promotional work has been undertaken over the last year including leaflets, videos, a self-assessment tool, a 3d house and a wide range of training. Development plans include further training for professionals and interested groups. Account will also be taken of the needs of people funding their own care but needing guidance on how to access telecare options.

The consultation demonstrates that despite progress in developing carers services over the last three years, many carers still feel unsupported and their needs not adequately recognised. Priorities of need highlighted by carers include:

- Information and guidance about local services
- Advice and guidance about aspects of dementia care such as challenging behaviour and incontinence, and knowing what to do in a crisis
- The need for regular breaks from the caring role
- A reliable single point of access for information, guidance, and emotional support

Carers want:

- Information about dementia and its possible impact and progression.
- An information 'checklist' for professionals involved in supporting people with dementia and their carers around the time of diagnosis of dementia, to ensure that core information is given consistently.
- Signposting to local and national information sources about dementia.
- Advice about legal issues (for example, lasting power of attorney), managing money and benefits/financial support for people with dementia and carers.
- Information about support available and key contacts for the future.
- A timely carer's assessment

5. Managing at more difficult times

The consultation feedback demonstrates the need to ensure a high quality of care for people with dementia living in care homes. Consultation information shows that necessary standards are not always met. **Workforce planning and training programmes should ensure that all care staff working in the residential sector have access to appropriate levels of dementia training.** Plans should address any barriers to achieving this, such as providers not being able to release staff for training.

People with dementia account for an ever increasing proportion of individuals entering long-term residential care. Use of Resources Best Practice Guidance indicates that 40% or less should be the target residential spend on long term residential and nursing placements. In 2011/12 the figure for Lincolnshire was 48%. Lincolnshire County Council is committed to achieving best practice in this area but diverting people to suitable alternative community support will require a strategic shift in funding. **Lincolnshire County Council and NHS partners will draw up plans to achieve this.**

When the capacity of the person with dementia declines carers want:

- Core information and advice at later points along the dementia journey and by all the different professionals who come into contact with carers and people with dementia.
- Access to or contact with mental health services
- Information about, and easy access to an assessment for social care support and regular reviews thereafter
- Access to a carers' assessment. These should always include questions about the carer's willingness and ability to continue caring and any support the carer needs to do so.
- Personal care at home provided by a small group of care workers who are trained to care for people with dementia.

- Practical support in the home, and recognition in assessments of social care eligibility and carers' assessments that practical support in the home can be important.
- Positive advice about coping with dementia.
- Information about common behaviour problems and positive strategies for dealing with them.
- Advice and support for carers in managing behaviour problems, including support from a mental health professional who knows both the person with dementia their carer.
- Information about, and the availability of, night sitting and night care services.

6. Inpatient Care

Acute Hospital Care

- Develop community services to avoid admission wherever possible
- Develop inpatient environments and staff skills to accommodate dementia patients appropriately
- Work in partnership with community Health and Social Care providers
- To expedite timely discharge and appropriate follow up
- Work in partnership with Mental Health providers to ensure mental health needs are appropriately met while in hospital and post discharge.

Mental Health Inpatient Care

- Develop community services for patients with complex needs to avoid admission to inpatient services where possible
- Review admission criteria and inpatient care pathway to ensure focussed treatment and reduce length of stay.
- Develop inpatient environments to meet the specific needs of dementia patients
- Separate dementia services from those for older adults with functional mental illness.
- Work closely with physical health providers to ensure the needs of dementia patients within Mental Health services receive timely and appropriate physical health interventions.

7. End of life

In this section of the consultation those responding said the fact that the wishes of patients and their families are respected is of paramount importance. This was reflected by the nature and number of responses received in this part of the consultation. Other priorities emerging were:

- Early planning for this stage whilst the person with dementia has the capacity to make decisions

- Guidance and information to enable the person with dementia and their family to plan
- Dignity and respect, honouring the wishes of the patient, providing good advice and information were all highlighted again. In addition, many respondents mentioned the need to provide help and support to families after the death of a loved one and during the grieving process.
- Clear information about different care options and where appropriate, information about residential care, including specialist providers for people with rare forms of dementia or early onset dementia.
- Active involvement of carers in decisions about end of life, in particular decisions about active intervention to prolong life and whether the person with dementia should be transferred to hospital at the very end of their life.
- Making a will and advance care planning. Carers, families, and advocates will be involved at the appropriate times
- The Dementia register should record that people have been encouraged by their GP to consider their preferences for care at the end of life.
- Where people are being cared for in a Dementia specialist setting, they have access to palliative care services e.g. Rapid Response Team when appropriate
- Staff who deliver end of life care to people with Dementia need separate training in both end of life care and Dementia care
- A Carers' Palliative Care Strategy to take into account the specific needs of people who are caring for a person with dementia.
- Workforce development plans will give care home staff access to End of Life training to increase their confidence in caring at palliative stages and reducing the need for acute hospital admissions in a crisis.

In Lincolnshire, we believe that living well with dementia also includes supporting a person with dementia to die well, or as they would have wished. So our vision for end of life care for people with dementia is:

- Supporting individuals with dementia to plan early for their future.
- Good person centred, joined up care.
- Being aware of the range of symptoms that a person with dementia may experience at the end of life and treating them.
- Supporting and helping the family and carers to understand what is happening at the end of life.

Planning for the future - It is vital that discussions with individuals living with dementia are started at an early stage to ensure that whilst the person has mental capacity they can discuss how they would like the later part of their life managed. People with dementia need to be supported to make advance care plans to make clear their wishes in these circumstances. Families may want to and will need to be involved with these discussions. It is important to recognise openly that there may be conflict between the person and their carer's wishes and preferences, for example regarding place of care. It is also important to recognise that people's

wishes can change, sometimes regularly. It is important that both the person with dementia and their families and carers have all the information they require in the way they require it to make an informed choice.

Joined up care - Many people have a role to play in end of life care – a GP, district nurses, care home staff to name a few – so the network can be large. But one of the most critical aspects to good end of life care is making sure that each member of the care team communicates reliably with others in the team.

Recognising someone with dementia is approaching the end of their life can be difficult. Health professionals should focus on anticipating a person's likely needs so that the right care can be provided at the right time. This early identification of people nearing the end of their life can trigger specific support, such as clarifying particular health needs, revisiting advance care planning discussions, and preventing crises admissions to hospital.

Symptom management - End of life care focuses on symptom relief not prolongation of life. Most of the symptoms experienced by people with dementia at the end of life, such as pain or swallowing difficulties, do not require specialist palliative intervention, but just good general care. However because of the common problem of loss of language skills in advanced dementia, symptom control can be a challenge. Where the patient shows a change in behaviour an exploration is warranted of the possibility of symptoms that require relief. It is important to exclude other causes of distress before assuming that pain or another symptom is the cause of the change in behaviour. Clinicians will follow a process of assessment, treatment and reassessment to identify the cause of the behavioural change and treat it. When caring for the whole person, it is also important to meet the spiritual needs of people with end-stage dementia; addressing these needs can give great comfort. For example, significant music can be helpful in bringing back memories of spiritual comfort to people whose language skills have deteriorated.

Family and Carers - When considering end of life care it is important to acknowledge that not only the person with dementia but also their family and carers will have needs. There is evidence that carers of people with dementia experience greater strain and higher levels of psychological distress than carers of other older people. Carers are entitled to an assessment of their needs. This assessment will require a review at intervals, and as a person approaches the end of life, the carers' assessment may need revisiting along with people's wishes and preferences affecting their advance care plan.

How we will measure success:

- Listen to feedback from carers and people with dementia at the end of life.
- Ensure End of Life training is established in other dementia training sessions
- Ensure that a training needs assessment and workforce development strategy is developed and incorporates End of Life
- Keep records to measure the numbers of people with dementia who :
 1. have an advance care plan
 2. achieve their preferences of place of care and death

3. die in their home or normal place of residence
4. are on a palliative care register

7. Our Vision for 2014-2017: Making the Strategy a reality

The Lincolnshire Joint Commissioning Strategy for Dementia Care has been developed in partnership with a wide range of individuals and organisations, using a variety of methods to identify the key priorities. An action plan is appended to this document and is based on realistic expectations of what needs to be achieved to meet the reasonable expectations of Lincolnshire people over the next three years.

All plans must be regarded as working documents, open to scrutiny and to review.

The plans however require the commitment and support of national, regional and local people and organisations to drive the changes we need to make to meet the aspirations of local people with dementia and their carers.

People affected by dementia need to know what support is available, when they can expect it to be available, and who will provide it. The NHS, local authorities and a wide range of independent and Third Sector organisations in Lincolnshire are committed to significant improvements. This strategy reflects both the National Dementia Strategy and the needs and aspirations of people with dementia and their carers living in Lincolnshire. The strategy applies to all people who are affected by dementia, those who have the condition and their families and carers, as well as those who work regularly with people with dementia and wider society.

Our aim is to develop a range of options at each stage of the dementia journey to enable families to access the help they need. This "core offer" will enable people affected by dementia to identify the sort of help and advice they can reasonably expect at any stage and who will provide it :

What we can offer	When it is available	Who will provide it
<u>Seeking help</u>		
Access to general information about memory loss and dementia and how you can find out more or seek help if you need to.	At the medical centre, social services office, library or other community facility	Medical centres Lincolnshire County Council www.MyChoiceMyCare.org.uk Voluntary organisations Care directories
<u>Getting a diagnosis</u>		
GPs and other medical professionals will take concerns about memory loss seriously and refer	At a medical appointment	General Practitioners Primary care professionals Hospital specialists Nurses

to a specialist service for diagnosis when appropriate		
If diagnosed with dementia you will be offered further information and advice in a way that best meets your needs and those of your family.	At a medical appointment	Medical Practitioners Health professionals Nurses
<u>Finding out more</u>		
You and your family are listed to and your concerns, needs and choices are acknowledged and addressed as positively as possible.	At a social care assessment. At a medical consultation	Social Workers Nurses Social care professionals Health professionals Dementia Family Support Service
<u>The right help at the right time</u>		
Access to services to help you stay at home and as independent as possible	At assessment or review. On request	Social care professionals Health professionals Voluntary agencies
<u>Managing at more difficult times</u>		
Access to appropriate health and social care services to help manage the condition. Support for family members to continue their care role for as long as feasible.	At assessment or review. On request	Health professionals Social care professionals Hospice at home services St Barnabas services
<u>At the end of life</u>		
Practical help to ensure your wishes and those of your family are respected. Palliative care available according to individual needs and wishes	When need for palliative care confirmed	Health professionals Social care professionals Palliative care services

8. Governance: Who will implement the strategy?

The joint Dementia Core Group, and the Health and Wellbeing Board for Lincolnshire will be responsible for agreeing an insuring implementation of all aspects of this Strategy and associated plans.

Partner agencies will set up a Dementia Programme Board. The Board will have defined executive functions and include representation at a senior level from Adult Care, Public Health, all Clinical Commissioning Groups, Lincolnshire Community Health Services, Lincolnshire Partnership Foundation Trust, United Lincolnshire Hospitals Trust, Lincolnshire Carers and Young Carers Partnership, Age UK, Alzheimer's Society and other major stakeholders.

The Board will have powers to mandate member agencies and working groups to deliver agreed tasks and report on specific parts of the dementia strategy.

Membership of the Dementia Programme Board will be countywide and represent a balance of statutory and non-statutory stakeholder interests.

Appendix A: Action Plan