

***'Living Well with Dementia'* in Lancashire**

Overview & Scrutiny Review

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Background to the review

At the Health Scrutiny Committee on 12 July 2011, members considered a report on the mental health inpatient reconfiguration proposals. The Chair noted that there was a lot of concern about dementia care and respite provision and suggested that a task group be established to consider those concerns and look at the timeline of services and support available to dementia patients and their carers. Members acknowledged the work already undertaken in the development of the Lancashire Dementia QIPP Strategy, which identified key integrated opportunities for improving the health and social care for those affected by dementia in Lancashire, and concluded that many of the services were already at a good standard and met the requirements of the National Strategy. However, they welcomed the identification of areas in which services could be further improved and co-ordinated and made more consistent across the county.

Members therefore agreed that a task group be established to review the services and support available to dementia patients with a particular focus on respite provision.

The Scrutiny Committee approved the request for a task group at its meeting on 16 September 2011.

Membership of the task group

The Task group was made up of the following County Councillors:-

- Fabian Craig-Wilson (Chair)
- Terry Aldridge
- Renee Blow
- Margaret Brindle
- Carolyn Evans
- Misfar Hassan

Scope of the Scrutiny exercise

The original scope of the task group was to review the services and support available to dementia patients with a particular focus on respite provision. Due to the range and complexity of services and support available for dementia patients the task group decided to break down the review into individual sections of the overall pathway of care. Therefore the scope of the exercise was to look at each of the following stages in detail:

- Prevention and early diagnosis
- Home and community based provision
- Residential care
- End of life care

Whilst the review would be broken down into individual topics it was agreed that cross cutting themes of training and communication would be addressed at each stage.

Members felt that the issue of respite care was a significant topic in its own right, and to enable a robust review of the related services and support agreed that they would briefly examine the issue in relation to dementia patients but would recommend that a further, separate task group be established to undertake a comprehensive review of all respite care services.

Methodology

Witnesses

The Task Group carried out a series of information and evidence gathering sessions. Discussions took place with a number of witnesses.

- Julia Pither – Integration Project Manager (Older Adult Network)
- Clare Evans – Social Worker
- Liz Wordsworth – Social Worker
- CC Mike Calvert – Cabinet Member for Adult & Community Services
- Dawn Butterfield – Head of Commissioning (North)
- Dr Ian Leonard – Associate Medical Director and Memory Assessment Lead Clinician
- Barbara Lowe – Professional Lead for Occupational Therapy
- Rebekah Proctor – Consultant Clinical Psychologist
- Rebecca Davies – Network Director, Mental Health Commissioning
- Debbie Nixon – Strategic Director, Mental Health Commissioning
- Beverley Page-Banks – Support Services Manager, Alzheimer's Society Central Lancashire
- Peter Sullivan – Adult Carer Support Officer, Preston & District Carers Centre
- Graham Towers – Carer
- Iain Pearson – Help Direct Manager (Help Direct Preston & South Ribble delivered by Age Concern)
- Barbara Rimmer – Dementia Advisor

Site Visits

Members visited a number of care homes in their own divisions to establish what specific services and activities are available for dementia residents; what training the care home staff receive to effectively understand the condition; and whether the physical environment aided orientation. Members produced a brief questionnaire with which to assist their investigations. (Annex A).

The homes visited included:

- The Broadway Nursing Home, South Shore, Blackpool
- The Victoria Residential Home, Burnley
- Dove Court, Burnley
- Lady Elsie Finney Care Home, Ingol

- Penwortham Grange Residential Care Home, Penwortham

Documents

The task group considered a range of documentary evidence including:

- Health Scrutiny Committee 12 July 2011, Item 7: Mental Health Inpatient Reconfiguration – Transitional Arrangements
- Minutes of Health Scrutiny Committee 12 July 2011
- Lancashire Dementia QIPP initiative – A Case for Change (Jan 2012)
- Centre for Public Scrutiny – Ten questions to ask if scrutinising services for people with dementia
- Department of Health – Case for Change: community based services for people living with dementia (2011)
- Department of Health – Case for Change: memory service for people with dementia (2011)
- Department of Health – Living well with Dementia: A National Dementia Strategy (Feb 2009)
- Department of Health - Quality Outcomes for People with Dementia: building on the work of the National Dementia Strategy (Sept 2010)
- Dementia Advocacy Network – Taking their side: fighting their corner.(Jan 2012)
- Alzheimer's Society - Dementia 2012: A National Challenge (March 2012)
- Alzheimer's Society - Worried about your Memory?
- Department of Health - End of Life Care for People with Dementia (2010)
- Lancashire County Council & Helen Sanderson Associates - Living well – thinking and planning for the end of your life (June 2010)

A range of information on websites was considered which included:

- www.dh.gov.uk
- www.alzheimers.org.uk
- www.cqc.org.uk
- www.lancashirecare.nhs.uk
- www.lancashire.gov.uk

Findings

What does the term dementia mean?

The term 'dementia' describes a set of symptoms which include loss of memory, mood changes, and problems with communication and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer's disease, and damage caused by a series of small strokes.

Dementia is progressive, which means the symptoms will gradually get worse and how fast dementia progresses will depend on the individual person and what type of dementia they have. Each person is unique and will experience dementia in their own individual way. It is often the case that the person's family and friends are more concerned about the symptoms than the person may be themselves.

Symptoms of dementia may include the following:

- Loss of memory – this particularly affects short-term memory, for example forgetting what happened earlier in the day, not being able to recall conversations, being repetitive or forgetting the way home from the shops. Long-term memory is usually still quite good.
- Mood changes – people with dementia may be withdrawn, sad, frightened or angry about what is happening to them.
- Communication problems – including problems finding the right words for things, for example describing the function of an item instead of naming it.

In the later stages of dementia, the person affected will have problems carrying out everyday tasks and will become increasingly dependent on other people.

The current picture

There are currently estimated to be around 17,600 people aged 65 and over in Lancashire with dementia, and these numbers are expected to rise to more than 25,600 by 2025. This increase is linked to the predicted rise in the number of people who will be aged over 85. There are also at least 317 people aged 64 and under who have dementia. Numbers in the 'under 65' age group are only predicted to increase by a very small amount.

However the Task Group were of the opinion that there may be many more people affected, who simply remain un-diagnosed.

[Living well with Dementia: National Dementia Strategy](#) was published by the Department of Health in February 2009. The vision set out in the National Dementia Strategy is for people with dementia and their family and carers to be helped to live well, no matter what the stage of their illness or where they are in the health and social care system. It seeks to:

- encourage help-seeking and help-offering (referral for diagnosis) by changing public and professional attitudes, understanding and behaviour;
- make early diagnosis and treatment the rule rather than the exception; and
- enable people with dementia and their carers to live well with dementia by the provision of good-quality care for all with dementia from diagnosis to the end of life, in the community, in hospitals and in care homes.

To support implementation of the strategy, £150 million was allocated to primary care trusts as part of their annual revenue allocation to fund the first 2 years of the national strategy. However, the funding was not ring-fenced and across the county little, if any, was directly used to implement the dementia strategy.

Subsequently, in September 2010, the coalition government updated the dementia strategy with the publication of [Quality Outcomes for People with Dementia: building on the work of the National Dementia Strategy](#). This set out four national priority objectives:

- improved early diagnosis and intervention
- improved quality of care in general hospitals
- living well with dementia in care homes
- reduced use of anti-psychotic medication

In response to the National Dementia Strategy, Lancashire County Council, NHS North Lancashire, NHS Central Lancashire, NHS East Lancashire, NHS Blackpool, NHS Blackburn with Darwen, Blackburn with Darwen Borough Council, Blackpool Borough Council, Lancashire Care NHS Foundation Trust and the Alzheimer's Society have worked in partnership to develop the Lancashire Outcomes Framework for Dementia. This framework provides a set of user and carer defined outcomes. The agencies that are partners to this agreement have all adopted these outcomes and used them as the foundation for development of local joint commissioning strategies for dementia. This ensures that delivery of the National Dementia Strategy across Lancashire is firmly rooted in the expectations and aspirations of local people who are affected by

dementia, either as sufferers themselves or as family members, friends or carers. In addition, a range of indicative outcome measures have been included in the framework to assist partners in developing local measures to track progress and improvement, as part of their dementia commissioning strategies.

A diagram identifying the different stages of the pathway is provided as Annex B

Training

Dementia training is one of the key objectives within the National Dementia Strategy and as such is an area of common interest for all agencies involved in supporting people with dementia. Therefore, as part of the work undertaken together to develop the Lancashire Outcomes framework, partners agreed to establish a time-limited multi-agency task group to consider whether there may be scope for collaboration and economies of scale in relation to dementia training. Partners involved in this project included LCC Commissioning, Personal Social Care, Training, Lancashire County Commercial Group, Lancashire Workforce Development Partnership, NHS North, Central and East Lancashire, Lancashire Care Foundation Trust and the Alzheimer's Society. The outcome of the work of this group was a set of dementia workforce competencies mapped against the types and numbers of staff across agencies who work in a role supporting people with dementia and the appropriate types, levels and costs of training required to meet the competencies identified. Due to the impact of the Comprehensive Spending Review on training budgets across partner agencies limited progress in terms of implementation has been made.

Improving Service Quality

In 2011 the Department of Health published the Dementia Commissioning Pack which included a set of contract inserts for a range of services. These contract inserts set out best practice and practical actions that providers can take to ensure that their services and staff are responsive to the needs of people with dementia and their carers. The inserts are relevant to both generic and specialist services since the majority of people with dementia are undiagnosed and are therefore likely to be accessing non-specialist services.

As part of the recent review of the Council's generic contract with domiciliary care providers the DoH contract inserts for domiciliary care have been included. Plans are in development to review and update the generic care homes contract which will also in future incorporate the DoH dementia contract inserts. These measures will help to drive up quality within the care sector

with all service users benefitting from the improved standards of care and in particular those with dementia.

Many people with dementia have co-morbid physical health problems that often prove challenging in general health and social care settings. Acute hospitals and care and nursing homes are key settings where people with dementia receive support. However, evidence across the country suggests this support and the support to those working with these people could be improved and developed to greater effect.

As part of the Quality Innovation Productivity and Prevention (QIPP) this project, led by the Lancashire Mental Health Partnership Team, is seeking to provide a basis for service and system redesign in order to support people more effectively, innovatively and at reduced cost to the health and social care economy of Lancashire. It has focused on the benefits of a coordinated approach, Lancashire wide variations and how a standardised approach in key areas will deliver improved quality and better performance. The Case for Change has four key areas of focus:

- Reviewing and reducing the use of anti-psychotic medication for people with dementia
- Acute General Hospital Care
- Memory Assessment Services and ongoing support following diagnosis
- Care/Nursing Homes and Community Support

Dementia Inpatient Facilities - Consultation

Evidence suggests that it is better to care for people with dementia in their own homes or community settings rather than residential care or hospital. In Lancashire, decreasing demand for inpatient services for people with dementia (in terms of both numbers of admissions and lengths of stay) has correlated with the work to develop community services over the past few years such that increasing numbers of patients with dementia are receiving treatment and assistance through local community services. During the last year approximately 93% of dementia care contacts were in the community, supported by specialist teams. Whilst the overall numbers of people with dementia is increasing as the population ages, the further development of a comprehensive range of community supports will mean that far fewer will require an inpatient admission. In the future, dementia inpatient services will be a very specialised service mainly for patients who require intensive care and support, whose behaviour cannot be managed in the

community. Most people with dementia will receive the care and support they need in their local community.

Lancashire Care Foundation Trust have worked with partners to develop a set of consultation proposals around the future provision of specialist dementia inpatient facilities and the parallel development of a comprehensive provision of community based dementia services in every locality across Lancashire.

This public consultation exercise will commence in early December

Area based examples of achievements and best practice:

North Lancashire

- Monthly drop-in sessions run by Memory Assessment Services and the Alzheimer's Society for people with dementia and their carers held in public venues during the day/evening.
- Early diagnosis: systems established to monitor numbers with dementia on dementia registers in primary care.
- Recovery-focussed care plans in place.
- The Intermediate Support Team are working with Care Homes to ensure residents with dementia are appropriately supported, offering advice, training and support.

East Lancashire

- Developed a bi-monthly 'Memory Matters' newsletter.
- Development of awareness raising toolkit including DVD for South Asian Communities.
- Advice and support given to several care homes around good practice re; environments for people with Dementia.
- Development of an Easy Read Dementia website.

Central Lancashire

- The dementia advisor service is now well established and the hours of the service have been extended.
- A DVD has been produced together with easy read literature to compliment the dementia advisor service.
- Establishing a risk share arrangement with general acute hospitals and local GPs to best manage the physical health needs of people with high level dementia care needs

- Brookside a development for enhanced care – 111 apartments with 24 hour support. Within Brookside there is Memory Assessment Service, the West Lancashire Dementia Advisors are based there, some Lancashire Care Foundation Trust are based there plus other community and carer focused activities and amenities such as a Bistro, Community Choir, 'Singing For The Brain' and music therapy.

The investigations of the task group were broken down into the key stages of the overall dementia care pathway. They spoke to a number of different stakeholders at each stage and their findings are detailed below

Early Diagnosis

There are many different types of dementia, although some are far more common than others and they are often named according to the condition that has caused the dementia

Alzheimer's disease is the most common cause of dementia. During the course of the disease, the chemistry and structure of the brain changes, leading to the death of brain cells. It is a progressive disease, which means that gradually, over time, more parts of the brain are damaged. As this happens, the symptoms become more severe.

Vascular dementia is the second most common form of dementia after Alzheimer's disease. It is caused by problems in the supply of blood to the brain. Vascular dementia affects different people in different ways and the speed of the progression varies from person to person. Typically, the symptoms of vascular dementia begin suddenly, for example after a stroke. Vascular dementia often follows a 'stepped' progression, with symptoms remaining at a constant level for a time and then suddenly deteriorating

Other types include:

- Dementia with Lewy bodies
- Fronto-temporal dementia
- Korsakoff's syndrome
- Creutzfeldt-Jakob disease

Further information on all these different types of dementia can be found on the [Alzheimer's Society](#) website.

Dementia comes into play when memory problems begin to effect the day to day live and cause problems with judgements and understanding, lack of concentration. When these areas start to change it has an enormous impact on day to day life.

The milder part of the spectrum has not been recognised until quite recently and people with dementia (mild forms) are still able to hold down a job etc. All dementias affect different people in different ways; but it is a progressive disease.

The difficulty in diagnosis is recognised as it can often be mistaken for depression. Blood tests can be done to eliminate other factors such as anaemia and, in the case of vascular dementia, high blood pressure and high cholesterol increases the likelihood.

There is a fear of diagnosis, and better communication of support and services may address this as often the public 'fear' it more than getting cancer. Strategy development has taken place in this area both at a national and local level and recent TV campaigns will hopefully start people talking about the subject as awareness raising helps to de-stigmatise the condition. Hope needs to be promoted through the management of the condition as currently there is no known cure.

In Lancashire, GPs are now more knowledgeable than they were a few years ago and the number of referrals has increased. They have a clear understanding of dementia in the context of all the other illness they deal with and they don't all need to be dementia experts, however it would help if GP practices had a dementia specialist but it's not a mandatory requirement. The wider Clinical Commissioning Groups will have a mental health specialist under which dementia will be included.

The people who tend to remain un-diagnosed are always the people with the milder forms of the disease and some people come to the memory clinics too late to make use of the support. The more information about what can be done, the more likely it is that people will seek help and that support can be provided for those going through diagnosis. We need to increase exposure to positive examples of living with dementia in families and communities.

Can medication help?

Some medication can improve the quality of life but there is a clear drive to reduce the amount of anti-psychotic prescribing nationally. The benefits of medication can be significant but they also have side effects. Evidence suggests that if the drugs work for the individual they will function better with them and it slows down the progression of the illness. However towards the later

stages they become less effective not because they've become immune to them but because the illness has become worse.

Aricept is used to treat mild to moderate dementia caused by Alzheimer's disease. It improves the function of nerve cells in the brain and works by preventing the breakdown of a chemical called acetylcholine. People with dementia usually have lower levels of this chemical, which is important for the processes of memory, thinking, and reasoning. The spend on Aricept by Lancashire Care Foundation Trust on has increased over recent years.

Medication is reviewed in the first instance and evidence has shown if it has worked for the first 3 months it will help for longer periods.

What can be done to prevent the onset of dementia?

Whilst it is not possible to prevent all cases of dementia, there are some measures that can help prevent vascular dementia, as well as cardiovascular diseases, such as strokes and heart attacks.

The best ways to prevent vascular dementia are eating a healthy diet, maintaining a healthy weight, getting regular exercise, drink in moderation, don't smoke and make sure that the blood pressure is checked and controlled

Alcohol has never improved anyone's memory and alcohol abuse is a factor in dementia onset – particularly if someone is drinking more than recommended into middle and old age.

There is some evidence that rates of dementia are lower in people who remain as mentally and physically active as possible throughout their lives, and have a wide range of different activities and hobbies. Evidence supports cognitive stimulation techniques – methods to aid the memory, such as regularly doing crossword puzzles. Support can be provided to help people choose things that suit them.

Physical activity helps due to increased oxygen to the brain, and dancing is another example as a routine is something that has to be learnt and remembered. Music is also very evocative in terms of recalling the time/place when a song or melody was first heard and the words of songs.

The key is to help people to help themselves – enabling people to manage their own lives.

Home/Community based support

Many people with dementia are supported by non-specialist community based services and that, in terms of helping people with dementia and their carers to live well with dementia means all services must be well equipped to understand and respond positively to the needs of people with dementia. The majority of care delivered to people with dementia at home and in the community is provided by family carers

A broad range of services are available to patients and their carers within Lancashire and some examples of these include:

Memory Assessment

Memory assessment services support the early identification and care of people with dementia. They offer a comprehensive assessment of an individual's current memory abilities and attempts to determine whether they have experienced a greater memory impairment than would be expected for their age.

Charnley Fold in South Ribble is an open access resource centre within a specifically designed environment for the needs of people with dementia. It provides a hub for memory assessment services, community mental health teams (older adults), consultant clinics, enhanced day support services, dementia adviser services, flexible outreach – community support to people with dementia, peer support meetings and carers groups and an open access information and advice centre for people with memory concerns, including a drop in café.

Help Direct

The Help Direct Advisors are aware of the issues surrounding dementia – but signpost to appropriate agency as they don't receive specific training in dementia or other memory conditions; however all staff attend 'safeguarding adults' training which covers all vulnerable adults. Guidelines are produced that advisors go through to filter which callers need additional support. It is a very hands on approach as visits are made if felt that they are needed.

Specific training would be beneficial. If trained it would help the advisors increase their ability to recognise certain subtleties of the condition.

A 'Well being measures' tool is used to determine how people are coping with their daily life. They measure this score at the beginning and end of their intervention so they can find out the level of increased resilience through the activities and support suggested.

Help Direct also signpost carers to various organisations and services that can provide the relevant respite care support.

Alzheimer's Society

[Dementia 2012: A national challenge](#). This updates the national dementia strategy that was produced in 2009 and looks at what is the actual experience of families and patients. It has three main areas of focus

- Driving improvements in health and care
- Creating dementia friendly communities that understand how to help – creating awareness
- Better research – it's been low on the financial agenda. Whilst there isn't yet a cure there have been great improvements in the care and support available.

CRISP – Carers Information and Support Programme. – This is an early stage 5 wk programme for people supporting a family member or friend with dementia. The friendly, confidential group sessions provide the opportunity for discussion about the experience of caring and provide information about dementia, legal and money matters, ways of coping day to day and getting help from local services. The Programme doesn't provide all the information all at once so the patient is not overwhelmed. Often once someone has been diagnosed people are then left alone, if they don't need any drugs or intense support at that stage. A lot of work has been done to contact people at the early stages and accompany them on their journey.

Dementia Advisor Service

Dementia Advisor Service (DAS) came out of the National Dementia Strategy. They visit people in their homes or can visit at a centre (e.g. Charnley Fold) – they are linked to a memory assessment centre. They can be with the patient for the whole journey and don't bombard them with all the available information at the point of diagnosis but take them through the stages as they get to them. Positive feedback has been received from patients who state that the DAS is very helpful.

The national campaign [Worried About Your Memory?](#) provides a range of guidance, one of which is a booklet that is designed to help people have a greater understanding of memory loss and the information and support that is available

There are definite gaps in services for people under 65 but the DAS however are able to try many different avenues to seek support. They also signpost to advice for benefits available, such as council tax rebate, disability living allowance, or carers funding.

Transport is a major issue in terms of gaps in service provision – often people are advised not to drive but many services are only efficiently accessed with a car.

Carers

A diagnosis can affect relationships – strain can be put on them especially if there is resistance to seeking help. The needs of carers of patients can be the same but they can also be very different.

Carers suffer higher than average instances of depression which in some instances may result in the dementia patient requiring alternative care. Problems can arise if the carer gets ill – there is an assumption by health and social care professionals that other family members will take over the care

It was felt there is a lack of suitable respite care and out of hours provision, particularly during weekend nights. A problem is that if a dementia carer wants to arrange respite care the actual patient doesn't want to deal with anyone else or let anyone else into the house. Dementia friendly care at home needs to be explored and needs to be far more intuitive and skilled rather than just task driven.

The financial strain also takes its toll on the family as the understanding of reduced financial income doesn't always register with the patient themselves.

It was acknowledged that it doesn't always help to meet with other carers of dementia sufferers as it can be too emotionally upsetting to discuss the future outlook for a person progressing through the illness. Instead it can be more beneficial to talk to carers of people with other conditions instead so they understand the issues of caring for someone without dwelling on the specific characteristics of the condition.

Residential & Nursing Care

With the provision of community based support and services, the aim is to keep people based in their own home as long as possible. However, it may get to stage where people with dementia need to go into a residential or nursing home. Many people with dementia move into a care home once their dementia progresses to a certain stage and some people with dementia have other illnesses or disabilities that make it difficult for them to remain at home

Good quality care that preserves dignity, treats people with respect and promotes independence can improve the lives of care home residents with dementia.

Challenges include finding good placements which offer the required skills, acknowledging the variable quality and availability of places and having to move long distances away from their families, which can be the case when people have very challenging behaviour

Choosing the right care home is, therefore, very important but it can be difficult.

Different types of care home

There are two categories of homes that are specifically registered to care for people with dementia. These are EMI (Elderly Mentally Infirm) homes offering nursing level care and EMD (Elderly Mental Dementia) which offers residential level support.

The type of home that the person requires will depend on their general health and care needs. Everyone with dementia is different. For some people with dementia the main problems that they experience will be dementia-related, whereas for other people with dementia their main problems may be caused by a different condition, such as a stroke.

Residential care homes provide help with personal care such as washing, dressing and eating. In some residential care homes staff have had specialist training in dementia care. Nursing homes provide personal care but also have a qualified nurse on duty 24 hours a day.

It is quite likely that dementia and non-dementia patients live in the same home.

All social, residential and nursing care providers must be registered with the Care Quality Commission, the independent regulator of all health and social care services in England.

Finding care homes in your local area

Lancashire County Council offer impartial advice and information to help families make the choice that is right for the person with dementia. Further information is available by telephoning Care Connect, the social care contact centre on **0845 053 0009**.

A social worker assessment can be carried out to determine the most suitable type of care required by the person and a directory of care homes in their local area can be provided. This is known as the County Council's 'Preferred Provider' (PP) list.

All homes included on the PP list are regularly checked and monitored by the County Council to ensure they provide high quality and personalised services, but the dementia patient and their family need to be aware that if they choose residential or nursing care from a non preferred provider that the County Council do not carry out any checks on these agencies.

Lists of local care homes and inspection reports are available from the [Care Quality Commission](#) (CQC) Their website provides the facility to specifically search for homes that specifically cater for dementia patients and details the latest results of inspections carried out to determine whether the home is meeting the required government standards.

Currently the PP list does not provide any detailed information on the standard or availability of care available and is generally just a list of names and contact details for a specific locality.

Many families of dementia patients have limited knowledge of the financial issues to be considered when a person needs residential or nursing home care and the social work team can assist with this aspect. Social Workers have financial knowledge of the benefits and assistance available and can arrange for council officers to do home visits for financial assessment.

Social workers are also based in hospitals and can support dementia patients and their families through the discharge process.

Not all social workers have dementia experience and additional training would potentially be able to address this. A mentoring system is in place and teams share knowledge and best practice through the discussion of individual cases but further staff development would be beneficial.

Greater integration of health and social care services could also help to address the promotion of good practice and develop bespoke 'dementia awareness' training opportunities.

A professional such as a doctor, or a voluntary organisation such as a local Alzheimer's Society, may also be able to give advice on the type of home that may be suitable for someone with dementia.

Examples of good practice in a care home include:

- Following the principles of person-centred care. This approach aims to see the person with dementia as an individual, rather than focusing on their illness or on abilities they may have lost.
- Creating opportunities for residents to spend time together and get to know each other through a wide variety of social opportunities.
- Encouraging people with dementia to maintain relationships with people outside the care home.
- People with dementia often need to have things to stimulate their interest and so an overly tidy environment is not always helpful.
- Spaces should be clearly signed and laid out to minimise any of the confusion or distress that people with dementia may sometimes feel.

It is estimated nationally that the number of places for people with cognitive impairment in institutions would need to rise by 63%, from 224,000 in 1998 to 365,000 in 2031, in order to keep pace with demographic pressures.

The tables below were taken from Lancashire Dementia QIPP initiative – A Case for Change Table A shows the number of people with dementia supported by Lancashire County Council in care homes as at August 2011.

Table A

Lancashire County Council	North	Central	East	TOTAL for LCC
Number of people with dementia supported in care home places	293	347	336	976

The cost of a dementia residential care home place in 2010/11 was £466.50 per week and the cost of a nursing care home place for someone with dementia was £595.50 per week. Table B shows all spend on people in care homes who have dementia over the full year 2010/11

Table B

Lancashire County Council	North	Central	East	TOTAL
Annual expenditure on people with dementia supported in a care home places (non nursing)	£7,033,849	£9,009,98 5	£7,644,873	£23,688,70 7
Annual expenditure on people with dementia supported in nursing care places	£1,717,667	£3,762,23 7	£2,063,703	£7,543,607
Total annual expenditure on people with dementia supported in care homes	£8,751,516	£12,772,2 22	£9,708,576	£31,232,31 4
... as a % of all care homes expenditure	51%	51%	43%	48%

Hospital based care

In Lancashire specialist dementia beds sit with the mental health trust which is [Lancashire Care NHS Foundation Trust](#), but this is not always the case across the rest of the country. Often it is the responsibility of the acute trusts instead.

Patients often end up in hospital as dementia means that the carer or residential home struggle to cope with their behaviour

Wherever possible, people with dementia in Lancashire are supported in their homes and in their local community through the provision of a range of good quality community services and support and over the last three years significant progress has been made towards achieving this aim.

These developments have resulted in decreasing use of inpatient services for people with dementia (in terms of both numbers of admissions and lengths of stay).

During the last year approximately 93% of dementia care contacts were in the community, supported by specialist teams. Consequently current usage of the existing 65 specialist dementia inpatient beds across 4 sites is operating at an average of 46 beds (70%). This suggests that further work is needed to re-invest this unused resource in the development of additional community resources, to ensure that more people can be supported at home and in their own community.

In the future dementia inpatient services will need to become highly specialised to meet the needs of a much smaller group of people who will generally have very complex needs and are likely to be detained under the Mental Health Act. The predicted numbers of people needing this type of service are very small – up to 30 people at any one time.

One example of the community resource provided by the Trust is the Nursing Home Liaison Team who respond to referrals from any nursing home that has a concern about a patient with a mental health condition. They provide advice and support on the management of patients.

They also provide on-going support and education to help staff become more knowledgeable in delivering person centred care, looking at alternatives to anti-psychotic medication to find alternative ways of managing challenging behaviour to provide a better outcome for the service user.

This service currently does not operate consistently across the county but following the wider mental health inpatient reconfiguration proposals consultation, due to start in early December, the intention is that by 2016, the Nursing Home Liaison Team will be able to deliver support and advice right across Lancashire.

Feedback on visits to residential and nursing homes

To establish what specific services and activities are currently available for dementia residents in Lancashire members of the task group visited a number of care homes.

The key findings included:

- Much evidence of best practice such as

- induction packages for staff which included training on recognising and coping with dementia symptoms
- showing and treating residents with kindness, dignity, respect, understanding and empathy.
- promoting independence
- 'Getting to know you' booklets completed by families
- Singing and music as reminiscence therapy used to stimulate and in some cases distract residents
- Using a variety of techniques to deal with challenging behaviour such as a short nap, diversion, distraction and the calming influence of specific staff members.
- ensuring knowledge and current best practice is updated.
- Support from GPs, fast referrals to local mental health teams.

End of life care (EoLC)

End of life care is normally defined as the care needed during the last year of life. Dementia presents challenges to this definition given the slow progression of most types of dementia, and identifying the time for a transition to EoLC will often be difficult.

Consequently, carers of people with dementia commonly underestimate the likelihood that a person will die in the next few months.

A particular feature of dementia, however, is that the individual's communication skills deteriorate so that the ability to express their views and wishes and to make choices is lost at an earlier stage than with other life limiting conditions.

In the future, Clinical Commissioning Groups will commission NHS services on behalf of individuals; therefore a real opportunity exists for GPs to be at the forefront of commissioning high quality EoLC services for people with dementia across the whole system and the care pathway. The National End of Life Care Programme has worked in partnership with the National Institute for Health and Clinical Excellence (NICE) to produce a commissioning guide for EoLC for people with dementia.

The majority of dementia patients in a residential or nursing home would remain there for the end of their life. Unless they are in significant pain there wouldn't be much benefit of moving them out

of the residential home to a hospice or hospital as it could be very distressing for them to be in unfamiliar surroundings.

Dementia patients should be encouraged to plan as early as possible before they are unable to decide for themselves and the County Council's social work team can again help with an assessment of a person's needs as they enter the final stages of their life.

This palliative care is the active holistic care of patients with advanced progressive illness, including the management of pain and other symptoms, and the provision of psychological, social and spiritual support. The goal of palliative care is achievement of the best quality of life for patients and their families.

Lancashire County Council have produced, jointly with partners, a guide called ['Living well - Thinking and planning for the end of your life'](#), based on the work in Central Lancashire by a group of people who were supporting family members, or working with people in residential care at the end of their lives. The guide is to help people think about and record what is important to them now, and what they want in the future when planning for the end of their life.

Conclusions

The Task Group reflected on the information and evidence they had considered throughout the review and arrived at the following conclusions:

Early diagnosis:

- Removing stigma and raising awareness would make it less scary and increase confidence in help available.
- Enable people to live well with dementia and help people to come to terms with their condition.
- Education about dementia is needed, skilling up the workforce across GP practices and other front line staff.
- Increase exposure of positive experiences.
- GPs could be encouraged to add a simple memory test to the periodical health checks already undertaken for blood pressure, cholesterol etc.
- Need to be planning now for what services will be required for the next 5/10/15 years due to predicted increase in number of people with dementia by 2025.

Home/community based support

- Alzheimer's website has a great deal of useful advice and guidance.
- It was acknowledged that due to the small numbers of patients under 65 (currently approx 317 in Lancashire) with dementia, the commissioning of specialist services was difficult. However it was felt that Help Direct would be able to signpost patients and carers and offer advice and guidance.
- The topic needs to be NHS driven in terms of commissioning services however, it's unlikely there's going to be any additional funding to deliver more services – so a different approach is needed. However, as the Cabinet Member for Adult & Community Services and the Cabinet Member for Health & Well Being both sit on the Health & Well Being Board they are in a position to request that issues, such as dementia services, are added to the agenda.
- Need a good business case to justify initial investment of training 'front-line' staff.
- E-learning could be a cost effective way of delivering basic awareness training.
- The Communications Team could promote positive messages of living with dementia and it might be useful to do some promotional work around myth busting.

Residential and nursing home care

- Adequate training for all residential and nursing home workers would enable a greater understanding of the condition and how to cater for the needs of the residents. The incentive to providers is that the training of their staff could be one of the criteria for the inclusion on the County Council's Preferred Provider list.
- The PP list could provide more meaningful information e.g. whether psychiatric nursing is available.

End of Life Care

- Opportunities to discuss end of life care could be incorporated into the overall care plans when a person moves into a residential or nursing home to ensure that the dementia patients' wishes are respected if they lose the ability to communicate clearly.

Recommendations

The Task Group therefore recommended that:

- The Health & Wellbeing Board is asked to consider how dementia services will be planned over the next 5 – 15 years to meet the predicted increase in demand.
- The Cabinet Member for Adult & Community Services is asked to consider an investment in basic training for all front line staff dealing with dementia in Lancashire.
- The Cabinet Member for Adult & Community Services is asked to consider the promotion of positive messages of 'living well with dementia' in Lancashire to encourage people to seek early support.
- The Cabinet Member for Adult & Community Services is asked to review the information provided on the Preferred Provider (PP) list and consider what improvements could be made to enable people to make informed choices about residential and nursing home provision.
- The Clinical Commissioning Groups consider a periodical memory test to be carried out at the same time as other health checks.

Acknowledgements

The task group would like to thank all those who gave their time and help to this investigation.

Questions to ask when visiting a Care Home

(taken from the CfPS document "10 Questions to ask if you are scrutinising services for people with dementia")

Although being supported to remain at home or in a housing facility such as extra care housing is the preference for most people with dementia, in some situations this will not be possible. For some, living in a care home provides the right balance between safety and independence, and access to activity and an understanding community. Unfortunately, good quality care is far from the norm – failure to communicate, over-use of antipsychotic medication to manage behaviour, lack of stimulation, inadequate nutrition, and lack of support from specialist mental health teams – is well documented.

A third of people with dementia live in care homes; up to 75% of people in non specialist homes have dementia, rising to 90-95% in homes for the elderly mentally infirm. That increase in the population with dementia means that although a greater proportion of people will be supported at home, the number of those requiring a care home placement is likely to remain similar to the current position. There is a considerable body of evidence for homes to draw on to provide excellent support. However, individual homes can only do so much to provide good quality care. They need to be supported within the wider system of the NHS, council and the voluntary sector. In particular, homes need to be supported by specialist mental health services that provide regular interventions rather than ad hoc or crisis support.

1. What measures are in place to improve training and education of staff to recognise and better deal with residents with dementia?
2. How do you ensure best practice in dementia care?
3. Do you provide regular activities to stimulate people with dementia such as art, music and Life story work? – Examples?
4. Is there a rich physical environment to aid orientation with assistive technology for prompts, reminders and communication?
5. Do you routinely use non pharmacological behaviour management strategies?
6. To what extent is there a local system of specialist mental health support for care homes? – e.g. does Lancashire Care Foundation Trust offer any nursing liaison service. (at present this type of service is only available in the east of the county)