

national dementia strategy

living well with dementia



Lancashire Multi Agency Outcomes Framework for Dementia

December 2009



Blackburn with Darwen **NHS**



introduction

Dementia is one of the most severe and devastating disorders we face. It is also very common. There are currently 10,355 people aged 65 and over in Lancashire with dementia and, in the next 20 years, numbers are expected to increase to 15,985. Although predominantly a disorder of later life, there are at least 317 people in Lancashire under the age of 65 who suffer from dementia. Dementia has a devastating effect on those affected and their family and carers and can affect everyone in society irrespective of gender, ethnicity and class.

Dementia sufferers typically experience a progressive decline in multiple areas of function, including memory, reasoning, communication skills and the ability to carry out daily activities. Alongside this decline, individuals may also develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which cause problems in themselves and which can complicate care. These features can occur at any stage of the illness.

Besides the devastating impact on those with the disorder, dementia also has a profound and negative effect on family members who provide the majority of care. Family carers are often old and frail themselves, with high levels of depression and physical illness, and a diminished quality of life. Carers can, however, be young people or even children. However, a great deal can be done to help people with dementia in terms of provision of information and advice, earlier diagnosis and intervention, as well the need for high quality care.

The National Dementia Strategy

‘Living well with dementia: A National Dementia Strategy’ was published by the Department of Health on 3 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.

To achieve this, it is proposed 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 achieve this by locating the responsibility for the diagnosis of mild and moderate dementia in a specifically commissioned part of the system that can, first, make the diagnoses well, second, break those diagnoses sensitively to those affected, and third, provide individuals with immediate treatment, care and peer and professional support as needed;
- 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.

The National Dementia Strategy identifies 17 key objectives which, when implemented, largely at a local level, should result in significant improvements in the quality of services and promote a greater understanding of the causes and consequences of dementia.

Lancashire Outcomes Framework & developing the framework

Lancashire Outcomes Framework

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.

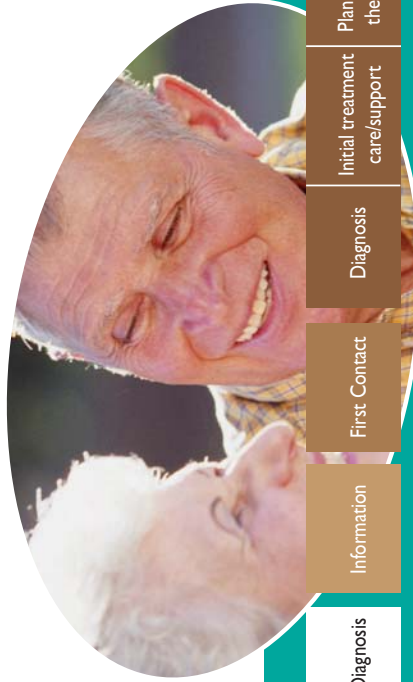
This framework provides a set of user and carer defined outcomes. As agencies who are partners to this agreement, we have adopted these outcomes and have committed to use them as the foundation for development of local joint commissioning strategies for dementia. In doing so we will ensure that delivery 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.

Developing the Framework

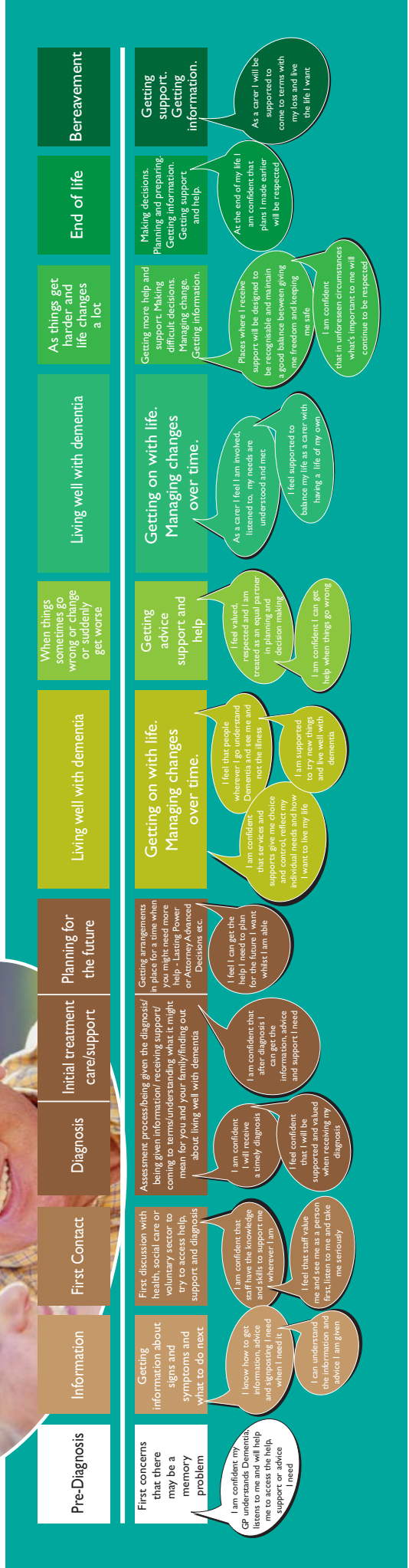
This framework was developed through a high level of engagement. People with dementia and their carers attended a series of workshops across Lancashire where they were supported to consider the outcomes that they would want, as they relate to the stages of the dementia timeline. The dementia timeline sets out the various phases that people with dementia experience and the challenges they often face, as their condition develops. A similar process also took place with several dementia and carer support groups across the county. The workshops deliberately focused on people with dementia and their carers, to the exclusion of professionals and other interested parties, in order to ensure that this outcomes framework is firmly rooted in the expectations and aspirations of those affected by dementia.

Qualitative analysis of the feedback received through the events and support group sessions was undertaken to produce a set of outcomes and work was undertaken within the partner agencies to develop the indicative outcome measures.

The framework was signed off and formally adopted by partner agencies in December 2009



lancashire multi agency outcomes framework for dementia



Outcome	Indicative Outcome Measure(s)
<ol style="list-style-type: none"> 1. I am confident my GP understands Dementia, listens to me and will help me to access the help, support or advice I need 2. I know how to get information, advice and signposting I need when I need it 	<ul style="list-style-type: none"> ● Proportion of all GPs who have received Dementia awareness training ● The proportion of people questioned who state that they are confident that their GP understands dementia ● The proportion of people questioned who indicate that their GP listens to them ● The proportion of people questioned who indicate that they feel that their GP will help them ● The proportion of people with dementia registered on QOF database in relation to the projected prevalence ● The number of carers of people with dementia registered on GP databases ● Number of Dementia related contacts to Customer contact centre and Help Direct ● Percentage of funding spent on Dementia related information, advice and signposting ● The proportion of people questioned stating that they know how to get information and advice when they need it

Outcome	Indicative Outcome Measure(s)
<p>3. I can understand the information and advice I am given</p> <p>4. I am confident that staff have the knowledge and skills to support me wherever I am</p> <p>5. I feel staff value me and see me as a person first, listen to me and take me seriously</p> <p>6. I am confident I will receive a timely diagnosis</p>	<ul style="list-style-type: none"> ● The proportion of people questioned indicating that they understand the information and advice they are given ● Number of staff who have received Dementia specific training ● Proportion of staff who have received dementia training as a proportion of those staff who needed to be trained ● The proportion of people being interviewed indicating that they feel valued when dealing with health and social care professionals. ● The proportion of people interviewed indicating that they feel they are listened to. ● The proportion of people interviewed indicating that they felt they did not have to wait too long for their diagnosis (or for the process of diagnosis to start if they haven't received their actual diagnosis at the time of the discovery interview)

Outcome	Indicative Outcome Measure(s)
<p>7. I feel confident that I will be supported and valued when receiving my diagnosis</p> <p>8. I am confident that after diagnosis I can get the information, advice and support I need</p> <p>9. I feel I can get the help to plan for the future I want whilst I am able</p>	<ul style="list-style-type: none"> ● The level of diagnosis against projected prevalence per locality ● The average time between referral to memory services and diagnosis ● The proportion of people interviewed who indicate they are confident that they will be supported when they receive their diagnosis. ● The proportion of people interviewed who indicate they are confident they will feel valued when they receive their diagnosis ● The proportion of people questioned who say they are confident they can get the information and advice they need after diagnosis. ● The proportion of people questioned who say they are confident they can get the support they need after diagnosis ● Percentage of people with a contingency plan? ● The percentage of people who feel confident they will have the help they need to put a plan in place

Outcome	Indicative Outcome Measure(s)
<p>10. I feel that people wherever I go understand Dementia and see me and not the illness</p> <p>11. I am confident that services and supports give me choice and control, reflect my individual needs and how I want to live my life</p> <p>12. I am supported to try new things and live well with Dementia</p> <p>13. I feel valued, respected and I am treated as an equal partner in planning and decision making</p>	<ul style="list-style-type: none"> ● The proportion of people in Lancashire saying they understand what dementia is. ● The proportion of people in Lancashire who say they understand the needs of people who have dementia ● Percentage of people with Dementia using Self Directed Support (SDS) ● The number of outcome based support plans for people with dementia ● The proportion of outcome based support plans for people with dementia where the outcomes have been achieved - as judged at review ● Percentage of people interviewed who say that they are treated as an equal partner in planning and decision making

Outcome	Indicative Outcome Measure(s)
<p>14. I am confident I can get help when things go wrong</p>	<ul style="list-style-type: none"> ● The number of carers with a contingency plan using Peace of Mind (POM) for carers expressed as a percentage of carers of service users with dementia
<p>15. As a carer I feel I am involved, listened to, my needs are understood and met</p>	<ul style="list-style-type: none"> ● Percentage of carers assessments for those caring for someone with Dementia
<p>16. I feel supported to balance my life as a carer with having a life of my own</p>	<ul style="list-style-type: none"> ● Number of carers using Self Directed Support (SDS)
<p>17. Places where I receive support will be designed to be recognisable and maintain a good balance between giving me freedom and keeping me safe</p>	<ul style="list-style-type: none"> ● 100 percent new premises / buildings for people with Dementia will be built with them in mind using set guidelines ● All existing Dementia specific premises will carry out self assessment using guidelines and produce an action plan

Outcome	Indicative Outcome Measure(s)
<p>18. I am confident that in unforeseen circumstances what's important to me will continue to be respected</p>	<ul style="list-style-type: none"> ● Percentage of unscheduled admissions of people with dementia to residential, nursing, specialist and general hospital beds ● Percentage of use of crisis support and intermediate care for people with dementia
<p>19. At the end of my life I am confident plans I made earlier will be respected</p>	<ul style="list-style-type: none"> ● Percentage of people with Dementia who died at home
<p>20. As a carer I will be supported to come to terms with my loss and live the life I want</p>	<ul style="list-style-type: none"> ● Amount of funding spent on carers post caring ● Amount of funding spent on Bereavement counselling

thanks

We would like to thank the following people who gave up their time to contribute to the development of this document:

Individuals with dementia and their carers who took part in the workshop events and support groups, for contributing their own experiences and aspirations to help generate these outcomes.

Dementia support groups throughout Lancashire for helping to support and co-ordinate the engagement with dementia sufferers and their carers.



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