

Dementia

a bold approach

Adults Health and Social Care Scrutiny Panel

Summary Report

April 2012

Calderdale
Council



Foreword

Calderdale Council's Adults Health and Social Care Scrutiny Panel has completed a detailed review of services to people with dementia. This booklet summarises the findings.

We have seen much that is good. The staff that we have met have been enthusiastic, committed and professional and there has been innovation.

But the larger picture is less rosy. The system is struggling with ever increasing demand. Understanding of dementia is high amongst specialists, but very patchy amongst staff more generally. People sometimes end up living in residential care when they are perfectly able to live in their own homes if they are provided with the right support.

We believe that, through a bold and radical commissioning strategy, significant resources that are currently allocated to looking after people with dementia in hospital or residential or nursing home care can be allocated to improving the primary care response to patients presenting with dementia and to increasing support to carers. We believe that this could create a virtuous circle, whereby hospital length of stay is reduced and residential or nursing home care admissions are delayed or avoided.

The messages from our review are consistent with the national policy drive and, in particular, the Prime Minister's challenge on dementia, which he launched in March 2012.

The challenge of supporting an increasing number of people with dementia is such that an incremental, piecemeal approach will not do. Which is why we are calling for **a bold approach**, resulting in a radical reshaping of services that will help people with dementia – and their carers – live longer, more fulfilling lives at home, rather than in institutional care.

Councillor Ruth Goldthorpe
Chair
Adults Health and Social Care Scrutiny Panel

April 2012

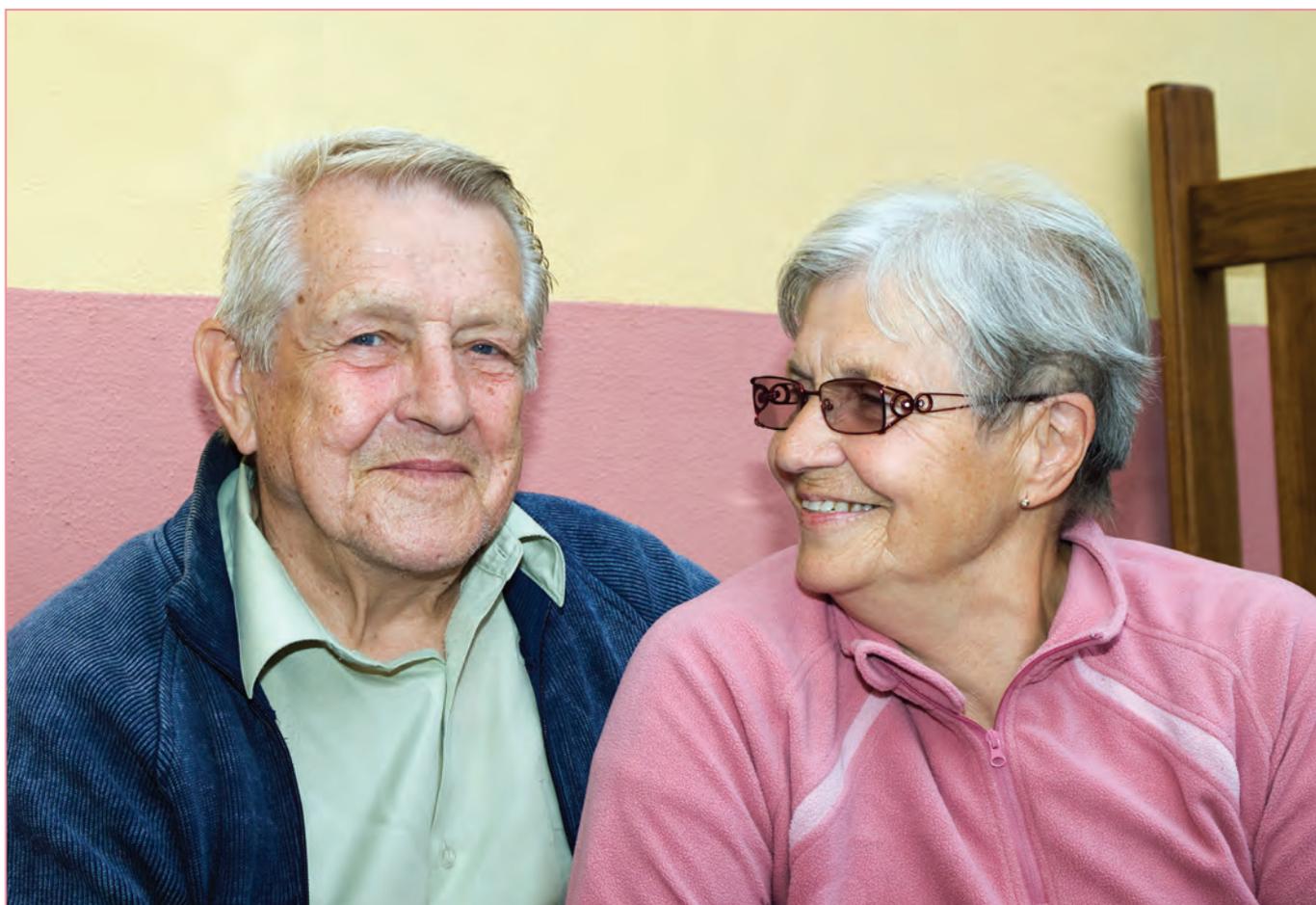
Recommendations

courageous commissioning

The money we spend on dementia services - £20m – could be spent more effectively. By making sure that that primary care services are well placed to increase rates of early diagnosis and to signpost people with dementia to advice services, admissions to secondary care because of crisis should be reduced and admission to residential or nursing care delayed.

We believe that the additional resource required to provide these services at primary care level can be found from resources currently spent in secondary care in general hospital and in residential and nursing care.

The Council and NHS Calderdale should amend the Joint Commissioning Strategy to redirect significant resource from secondary hospital care and residential and nursing home care to primary health care services to provide for greater identification of people with dementia, earlier diagnosis, and enhance community support and support for carers.



dementia is everybody's job

We met many committed hard working and – in some cases – inspirational members of staff from the Council, the NHS and the community and voluntary sector during our review. But we also heard that people employed in general roles or in other specialisms sometimes have a limited understanding of dementia.

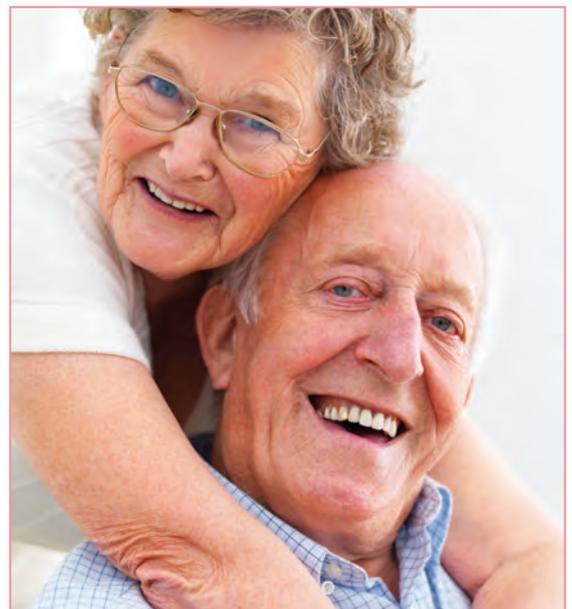
We consider that many staff employed by the Council or in the NHS need a basic level of awareness about dementia. As well as professional staff such as doctors, nurses and care staff, receptionists, domestic staff in care settings and people working in telephone or face to face advice services need to understand that some people will react differently and have different needs.

The excellent Butterfly Scheme should be extended to all wards at Calderdale Royal Hospital. This can only happen if dementia champions are identified for each ward and staff at all levels on each ward have the appropriate level of training.

a dementia friendly Calderdale

Dementia is on everyone's street and in everyone's market square. As we grow older as a country, more and more people are living with dementia, either because they have the illness, or are caring for someone with the illness. We all use the same shops, buses and restaurants and these services and businesses could – with a little effort – be more accessible for people with dementia.

A cross-agency dementia training strategy should be developed and funded. The strategy should include specialist training for those staff whose job is devoted to the care of people with dementia. It should also include a more basic level of training and awareness-raising for those providing more general care services. The strategy should not be limited to staff working in care services, but should include staff working in other services, such as Customer First or libraries.



Margaret and Edward Hever agreed to share their story:

Edward takes a matter of fact approach to the future. "Knowing that I have Alzheimer's, means that I have the chance to get things in order."

There are good days and bad days. "Sometimes it feels as though my feet are stuck to the floor," says Edward. "Sometimes I hallucinate."

"I will find him talking to people who he imagines are there," says Margaret.

"There are times when if Edward wants to get somewhere, he will turn the wrong way."

But on good days they still enjoy life to the full. They love holidays abroad and Edward – who always took a leading role in local amateur operatics – is an enthusiastic participant in the Third Age Choir, which meets at Waring Green. He does the sound system at his local church and has organised two fundraising concerts for the Alzheimer's Society. Last year the couple even attended a Royal garden party at Buckingham Palace.

We would like to see Calderdale working towards becoming a dementia friendly borough.

The Cabinet should set an objective of Calderdale becoming a dementia friendly borough by April 2014.



Edward and Margaret Hever

a visit to the doctors

Margaret and Edward Hever share their story:

It was more than two years after Margaret first suspected that there was something wrong with her husband that doctors confirmed that Edward had Alzheimer's disease. "I had an inkling that something was wrong. He was forgetting bits of things . . . there was just something about him that was not right. He would ask me what day it was and then ask me again an hour or so later."

For many people, their first port of call when they have concerns about their memory – or about that of a family member – is their family doctor. But, according to the National Dementia Strategy, only about one-third of people with dementia receive a formal diagnosis at any time in their illness. When diagnoses are made, it is often too late for those suffering from the illness to make choices.

Getting things right when people are first worried about their memory is probably the most significant change that needs to be made to improve services for people with dementia, because, from this initial point of contact, so much else flows.

Primary care should be recognised as the key entry point to the "dementia care system" and primary care services should be geared up to provide earlier diagnosis and support and advice services that are easily available, preferably on-site. We believe that there is scope for a pilot project to test how this could be developed with a small number of primary care practices.

The revised dementia strategy should include a particular focus on increasing rates of diagnosis and on making earlier diagnoses.

The revised dementia strategy should give emphasis to the importance of primary care as a gateway to dementia services and should develop approaches that enhance the services available within primary care, including advice and support services.

NHS Calderdale should consider a pilot project in primary care to test the impact of increased investment in the support available for people with dementia that is provided within primary care.

carers as the main care providers

Margaret and Edward Hever share their story:

“When we found out that Edward had Alzheimer’s, I was really angry . . . not with anyone in particular, but with the situation we were in,” says Margaret.

Some of the most compelling evidence we have heard was from the carers who spoke to us. They told of a well-meaning system that sometimes failed them. A system that drove people with dementia down certain paths, without always stopping to think about what they – and their carers – wanted.

The Carers’ Strategy should make particular reference to dementia, so that the Council, the NHS and other organisations make sure that they listen to carers as well as people with dementia.

Comment from a helper at a Calderdale Dementia Cafe.

“I help out at the dementia cafes because I saw how it affected a member of my own family.

“The cafes help people with dementia and their carers to get out and talk about the condition.”

The revised Carers’ Strategy should pay particular attention to the needs of carers of people with dementia.



in hospital with dementia

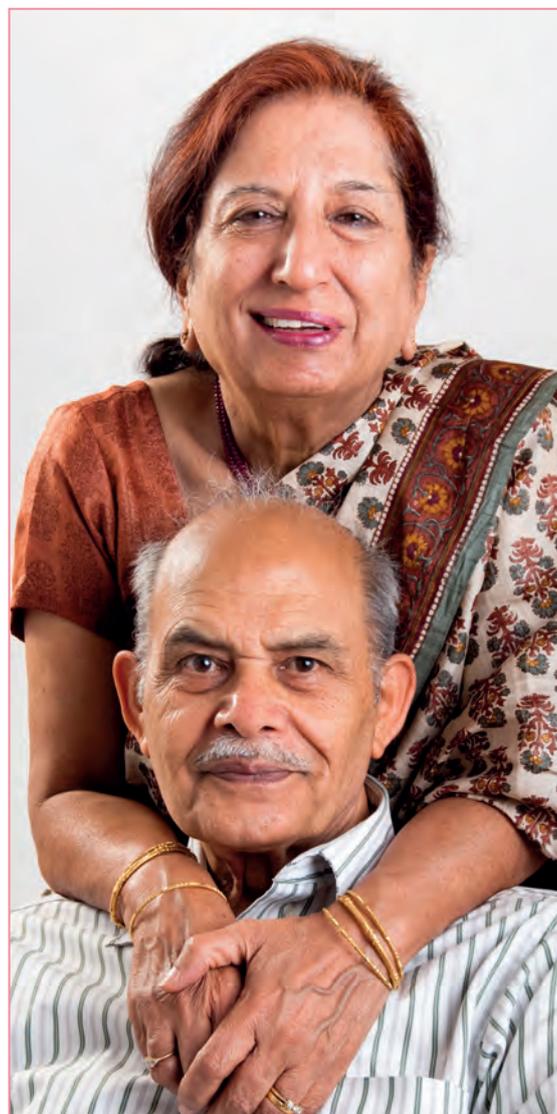
Older people form an increasing proportion of those who occupy hospital beds and a large number of those will have some degree of dementia. These are people who have been admitted to hospital not because of their dementia, but through suffering another illness or injury.

The Butterfly Scheme, where a patient with dementia is identified by a butterfly emblem placed on their bed is a simple, but effective way of helping ensure that patients get appropriate care. We should like to see it extended throughout the local hospitals.

Lack of widespread awareness of the needs of people with dementia is one of the key factors leading to people with dementia having significantly longer lengths of stay than other patients in acute hospital.

We heard about some imaginative and innovative uses of assistive technologies as a means of maximising independence. In one instance, the wife of a person with dementia was woken by an alarm when her husband woke in the night. This meant that she did not lie awake worrying about him, but was able to sleep until she needed to help him. This also reduced the consequences of his disruptive behaviour when he woke. Assistive technologies can be a cost effective way of providing much needed reassurance and support for service users and their carers.

People with long term conditions such as dementia can benefit hugely by a personalised approach to care services, where they – and their carers – can manage their care themselves. This will often mean that they have personalised social care and health budgets.



The Butterfly Scheme allows people with memory impairment, in conjunction with their carer, to request a specific care response from all hospital staff. This request is expressed discreetly via the Butterfly Scheme's symbol, which prompts all staff to activate the scheme's simple five-point response, promoting the patient's well-being and safety. Carers are also invited to offer specific insights into personalised care for their loved one, via an integral carer sheet which all staff can then access.

Barbara Hodkinson
Founder and Coordinator of the Butterfly Scheme

The Butterfly Scheme should be extended to all appropriate wards at Calderdale Royal Hospital and Huddersfield Royal Infirmary.





The Council, Calderdale and Huddersfield NHS Foundation Trust and South West Yorkshire Partnership NHS Foundation Trust should work in partnership to ensure that services and procedures are in place to maximise discharge from Calderdale Royal Hospital and Huddersfield Royal Infirmary to home or intermediate care, rather than to residential or nursing home placements.

The Council should seek to make extensive use of assistive technologies to help service users maximise their independence and to provide support and reassurance for their carers.

The Council and the NHS should work towards increasing significantly the number of services users with dementia who have personalised social care and health budgets so that they have far greater control over their packages of care.

The Adults Health and Social Care Scrutiny Panel is one of Calderdale Council's five Scrutiny Panels. Its seven Councillor members are responsible for undertaking detailed reviews such as this and for scrutinising the work of the Council with older people and vulnerable adults and for scrutinising local NHS provision.

A copy of the full report is available at www.calderdale.gov.uk or contact Scrutiny Support, Democratic and Partnership Services, Room 23, Town Hall, Crossley Street, Halifax, HX1 1PS
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Published as part of Calderdale Council's Adults Health and Social Care programme of raising awareness about dementia

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