



A BOLD APPROACH

ADULTS HEALTH AND SOCIAL CARE SCRUTINY PANEL

REPORT OF A REVIEW OF SERVICES TO PEOPLE WITH DEMENTIA

April 2012

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foreword...

I am very pleased to present the report of the Adults Health and Social Care Scrutiny Panel review of services for people with dementia. Members of the scrutiny panel have visited services, talked to managers and professional staff in the Council and the NHS, but, most importantly, have listened to what people with dementia and their carers have said to us.

We have seen much that is good. The staff that we have met have been enthusiastic, committed and professional. There has been innovation, such as the Butterfly Scheme. Carers have been unanimous in their support for the work of the Alzheimers Society.

But the larger picture is less rosy. The system sometimes seems to be struggling with ever increasing demand. Understanding of dementia is high amongst specialists, but very patchy amongst staff in more general roles. The system can seem to drive people into more formal – and expensive care- and cannot always operate flexibly enough to support people better and longer in their own homes.

Our review was punctuated with announcements from Government and national organisations about the need to find community alternatives to looking after people in general hospitals, identify care for people with dementia as a priority in the NHS Outcome Framework, and perhaps most importantly, recognising the right of older people generally, in people with dementia in particular, to be treated with dignity. So it feels that our work and our recommendations are consistent with the national policy direction.

We hope this means that our recommendations will be received enthusiastically. But an enthusiastic response followed by a timid plan that only tinkers at the edges will make only the faintest difference. We believe that this is time for a bold approach - one which will make transformational commissioning decisions that will shift resources that can be measured in millions not in thousands. To embark on staff development plans that improve the skills and awareness of most of the staff, not the few. And to find new and different ways of involving people with dementia and their carers not just in planning their own services, but in planning the general shape of services.

Our last recommendation is that we revisit dementia services in November 2012 to assess progress. There is a golden opportunity to undertake some speedy transformational work and we look forward to seeing substantial progress by then.

I would like to thank everyone who has contributed to this review. Everyone has gone out of their way to be helpful, change their schedules to meet us and to supply us with all the information we needed.

**Councillor Ruth Goldthorpe, Chair, Adults Health and Social Care Scrutiny Panel
March 2012**

a bold approach.....

We have found much good practice and some fantastically skilled, enthusiastic and professional staff within dementia services. But – on its own – this is not enough, particularly in the context of the increased needs that have been set out in Chapter Four of this report.

The current Dementia Strategy and its associated Action Plan has helped make progress. But it is an “understated” strategy and one that has not been adopted formally by the Council’s Cabinet or by the NHS Calderdale Board.

The current strategy was produced after an extensive consultation exercise and is a sound foundation for taking dementia services forward.

However, we believe that there is a need to reframe the Dementia Strategy so that it sets out a high level commitment from the Council, the NHS and other partners to developing new ways of supporting people with dementia and their carers. This report proposes areas that should be given prominence in a revised strategy.

Everyone involved would like to see increased resources identified for services for people with dementia. But there are many important and competing demands for resources and, in the current economic climate, services need to work hard to provide more and better outcomes for the same or fewer resources.

There is a policy drive, both nationally and locally to reduce the length of time people spend in acute hospitals.

Mike Farrar, the Chief Executive of the NHS Confederation, said in December 2011,

Hospitals play a vital role but we do rely on them for some services which could be provided elsewhere.

We should be concentrating on reducing hospital stays where this is right for patients, shifting resources into community services, raising standards of general practice, and promoting early intervention and self-care. The old hospital-based system has to develop into a more preventative, community-based system. There is a value-for-money argument for doing this, but it is not just about money and the public need to be told that - this is about building an NHS for the future.

The World Alzheimer Report 2011 concluded,

Available evidence suggests that governments should “spend to save” – in other words, invest now to save in the future. Economic models suggest that the costs associated with an earlier dementia diagnosis are more than offset by the cost savings from the benefits of anti-dementia drugs and caregiver interventions. These benefits include delayed institutionalisation and enhanced quality of life for people with dementia and their carers.

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.

Members of the Adults Health and Social Care Scrutiny Panel presented the *dementia service model* set out in the next chapter of this report to a seminar of Council, NHS and community and voluntary sector professionals on 3 February 2012. It is the foundation for the more detailed chapters and recommendations that follow.

Senior managers from the NHS and the Council met with the Adults Health and Social Care Scrutiny Panel on 4 April 2012 to discuss their business plans for dementia services for 2012/13. They demonstrated major commitment to addressing the dementia challenge and told us about progress even in the few months since we completed our evidence gathering. We still feel that there is a need to examine carefully how we commission services to make sure that the whole system is “joined up” and so Chapter 6 of the report, *courageous commissioning*, remains highly relevant.

On 26 March the Prime Minister, David Cameron, launched his own “challenge on dementia”, which is consistent with our own challenge and findings. This should give even greater impetus to those responsible for dementia services to take forward our recommendations.

This is not a critical report and it offers no unique insights or magic solutions. It does identify an opportunity to take advantage of the policy drivers that we have touched on above and the need to make most effective use of our scarce resources. It seeks a redirection of focus to increased diagnosis of dementia, earlier diagnosis of dementia, and the provision of earlier support and advice. These changes will challenge some existing services and attitudes. But it is only a bold approach that will provide the transformational change that is needed to deal with the scale of this issue.

recommendations...

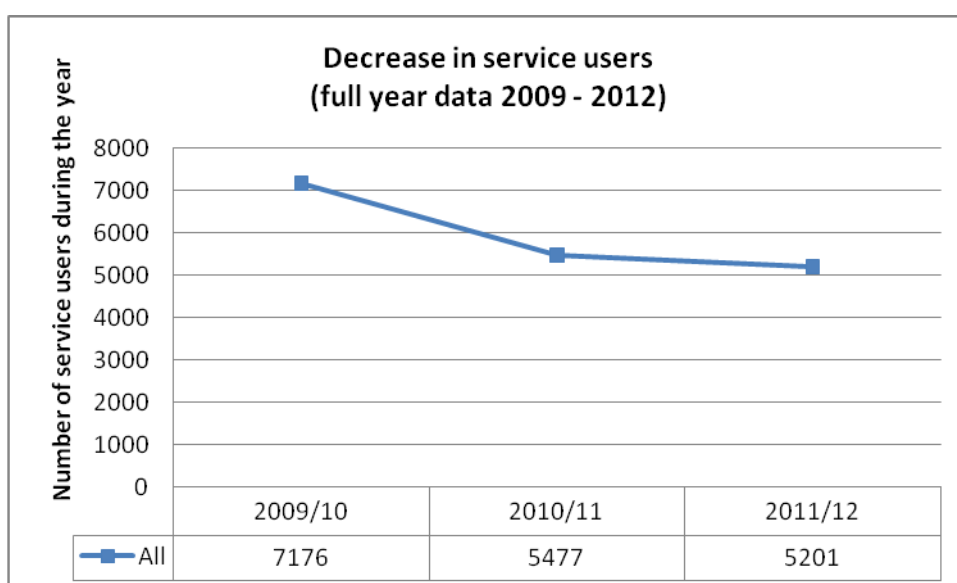
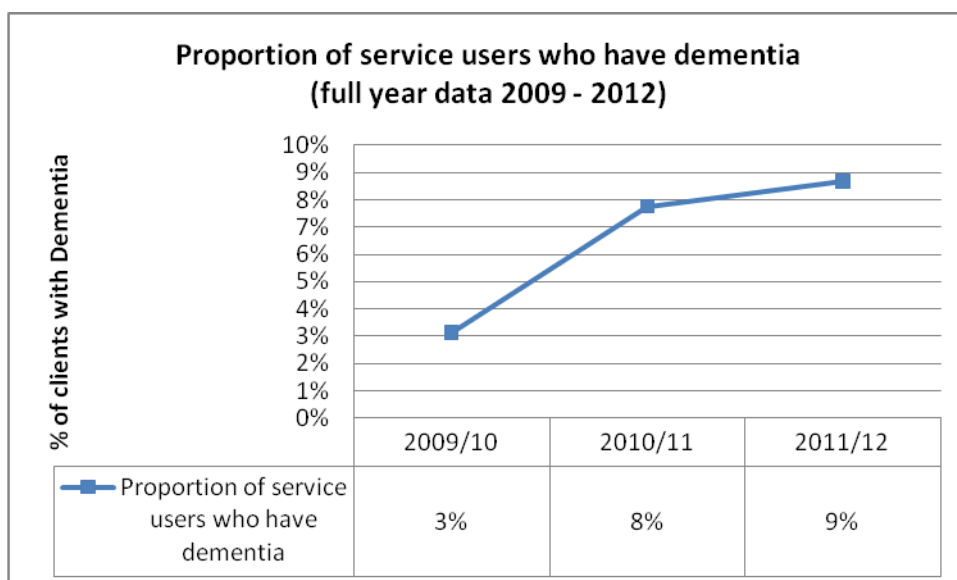
1	The Council and NHS Calderdale should amend the Joint Commissioning Strategy to redirect significant resource from secondary hospital care and residential and nursing home care to primary health care services to provide for greater identification of people with dementia, earlier diagnosis, and enhance community support and support for carers
2	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
3	The Cabinet should set an objective of Calderdale becoming a dementia friendly borough by April 2014.
4	The revised dementia strategy should include a particular focus on increasing rates of diagnosis and on making earlier diagnoses.
5	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
6	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
7	The revised Carers' Strategy should pay particular attention to the needs of carers of people with dementia
8	The Butterfly Scheme should be extended to all appropriate wards at Calderdale Royal Hospital
9	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
10	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
11	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
12	The recommendations of the National Audit of Dementia Care in General Hospitals 2011 should be implemented in full and progress reported in the Quality Account

facts and figures.....

This chapter of our report sets out some of the contextual information for our review.

Social Care Service users during the year (April to March)

Service users Full Year			
	Dementia	All	Proportion of service users who have dementia
2009/10	225	7176	4%
2010/11	425	5477	8%
2011/12	452	5201	9%



Population of Older People

The number of older people living in Calderdale is forecast to grow rapidly over the next 20 years. By 2029 there will be 25,900 people over the age of 75 living in the Borough, a 69% increase from now. This means that part of the population in Calderdale will have greater and more complex needs. Services will need to be responsive to these changes and to plan for workforce and other business implications.

Over 3,500 older people receive adult social care services funded through Calderdale Council each year, 11% of all older people living in the Borough. A third are supported through preventative community alarms, falls monitors and meals services. Of the 2,500 who require more intensive support one in three are referred through the hospital. Of those who are referred from community settings, nearly half seek support at the point when their carer is tipping into crisis.

The number of older people admitted into long term 24 hour care is increasing by 3.5% each year and the nature of that demand is changing with increasing need for:

- Short term respite placements for people whose carer is in crisis
- Short term intermediate care placements for people who need nurse led rehabilitation as they are discharged from hospital
- Nursing beds for elderly, frail people with multiple, complex needs arising from dementia and end of life care needs
- The number of older people accessing home care has remained relatively stable, however the average care package size is rising as people are presenting with more complex, multiple needs

Take up of traditional building-based day services by older people is in decline, a process which is being accelerated as the Resource Allocation System (RAS) rolls out take up of personal budgets.

The expectations of people who are ageing in the future will be very different to those of people currently receiving services. As well as increasing demand for housing, health and social care services it is anticipated that there will be a rising demand for innovative and age-relevant cultural and leisure services for an increasingly diverse population.

Changes in the Number of People with Dementia

Dementia UK estimates that 1 in 20 people over 65, and 1 in 5 over 80, are affected by dementia. In Calderdale, estimates based on national prevalence rates indicate that 2,303 people could have dementia. Over the next 20 years the number of older people is set to rise dramatically, meaning that the number of people with dementia will also rise by 75% to 4,042 people by 2030.

The following tables illustrate the increasing expected prevalence of dementia in Calderdale. The table below shows how significantly the prevalence of dementia increases in the 85+ age group.

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

The prevalence of dementia in the 85+ age group is a key factor for Calderdale. In addition the faster rate at which dementia is prevalent in women is of particular concern due to the high proportion of people over the age of 65 who are women. The gender gap indicates that national rates could underestimate the extent to which dementia is prevalent in Calderdale. Commissioning for change also needs to take account that 17.3% of all people over the age of 60 live in households that are income deprived and that 37% of people over the age of 65 live on their own. What the growth in numbers of people with a dementia means for Calderdale over the next 20 years is shown below:

65 and Over			85 and Over		
2010	2030	% Change	2010	2030	% Change
2,303	4,042	75%	1,069	2,042	91%

The expected rise in numbers of people with need and resulting growth in demand for support and services represents a significant challenge to existing and traditional services. It is essential to recognise this shift in the age profile to enable effective planning and commissioning in anticipation of increasing demands for good quality, flexible services to meet the changing needs and expectations of people with dementia and their carers.

Calderdale's strategic objective in relation to dementia is to narrow the gap by 10% between the number of people who are known to have a dementia and the number of people that would be expected from the Dementia UK report.

At the start of implementing the strategy 850 people were known and recorded on the GP registers with a diagnosis of dementia. The target required that a further 85 people be identified and diagnosed. By October 2011 the target had been exceeded; - 168 new diagnoses have been made and 1018 people are now known to have a dementia by their GP. The gap between prevalence rates and diagnosis is, however, still a 55% variance which means half of those who may have dementia are still not yet known to services. Early identification and support continues to be a priority for implementation of the local dementia strategy.

Market Position Statement: Dementia Services

Community Preventative Services (Alzheimer's Society, rethink and Age Concern Calderdale & Kirklees)

NHS Calderdale and Calderdale MBC jointly contract for provision of general advocacy services for older people with dementia and for Independent Mental Capacity Advocates which will be provided from April 2011 by rethink. The cost of advocacy services is around £130k each year.

Alzheimer's Society provides two community cafes for people with dementia and their carers funded from their own reserves. The cafes operate on the 1st and 3rd Wednesday in every month in Halifax and in the Lower Valley area. In addition Alzheimer's Society provides family support through an annual grant from Calderdale Council of £14,470.

During summer 2011 the Council and NHS Calderdale tendered for a peer and carer support service and an early support following on from diagnosis service. Alzheimer's Society won both tenders. The annual costs of these new services are £150k per annum. They are being funded through the Social Care for Health Benefit funding which was passed from NHS Calderdale to the Council. The monies are non-recurrent beyond 2012/13.

Age Concern opened a new facility based in the Woolshops in February 2011 providing older people and their carers easy access to information, advice and guidance to support and maximise and sustain their independence. The service operates on a traded services model for people who are self funding their care options and provide access to a range of services including:

- Telecare including the 'Just Checking' software solution for dementia
- Handyman adaptations to make the home safer for a family with dementia
- Minor adaptations
- Equipment
- End of life planning including wills, legacies and funerals

The Council has invested £30K in *Just Checking* assessment software which is being rolled out in autumn 2012. The software is used when a person is referred to the Council for a 24 hour long term care home admission due to dementia. *Just Checking* is installed for up to a 6 week period to determine if an admission is really required or whether, through telecare and community services, a person can remain independent at home.

Housing Related Support

There are 130 Extra-Care housing units available across the Borough in 3 developments, of which 19 are taken by people who have dementia or early onset memory difficulties. The average care package (rent+ service charge+ care) is £348 per week per person and the average spend on 19 places is £344,000 per annum

Community Day Services

Calderdale Council and NHS Calderdale jointly invest £1.9m per annum in community based day services for older people in the Borough. NHS Calderdale contribute £500K towards the total investment which purchases 60 places for adults with dementia. The 60 places are all provided within the Council in-house day service. The unit cost per place is £8,333 per annum. The Council and NHS Calderdale are currently reviewing this arrangement to ensure that anyone with dementia will receive support from a specialist nurse regardless of who runs their day services. The outcome will require extending coverage to Age Concern's day services and the services provided by Heath Stroke Club and other providers delivering to older people.

Home Care

The Local Authority Provider Service is piloting a specialist home care service for people with dementia. The team "went live" from December 2010 at a cost of £150k per annum. By summer 2011 the team was providing support to 28 people.

Community Mental Health Teams

There are 2 Community Mental Health Teams dedicated for older adults with mental health problems at a cost of £1.3 million. The teams are multidisciplinary offering specialist assessment, treatment and care with mental health problems in their own homes and the community and saw 651 people in 2009/10. The memory clinic costs £219k a year and saw 383 people in 2009/10.

NHS Inpatient Admissions

The 16 bedded inpatient assessment and treatment for older people with functional mental health problems who cannot be cared for in the community or other settings due to the intensity and expertise of the care required. NHS Calderdale commissions this service at a cost of over £2 million per annum.

Dementia Residential and Nursing Care Home Admissions

There are eight care homes in the Borough who have registered with the Care Quality Commission to provide specialist care for dementia in residential homes and four for dementia in a residential home with nursing. A new-build home with nursing is opened at the end of 2011 and a further residential setting is opened in March 2012. In addition NHS Calderdale commission 12 beds with an independent sector provider for a total contract value of £782k.

At January 2011 there were 80 people with dementia placed in residential care homes of whom 14 were funding the full cost of their placement themselves. A further 19 people with dementia were placed in nursing care homes. The average cost per resident week for a dementia residential

placement was £440 and the average for a nursing care home with dementia specialism was £573. Care home placements for people with dementia accounted for 16% of all placements for people over the age of 65, significantly above prevalence rates for dementia in the general older population.

A review of people placed through Calderdale Council and NHS Calderdale into a care home identified multiple triggers were usually present. As the new dementia pathway is implemented it is anticipated that there will be a reduction in the number of people with moderate needs due to their dementia who are inappropriately placed into care home settings, however this change will be incremental over time as earlier identification enables early intervention and support. In the short term it is anticipated that demography will drive up demand for placements, an assumption which is reinforced by the 7.5% rise which has taken place since 2009 in the number of older people placed in care home settings.

Where a care home placement is arranged for a person with dementia they often present with complex and multiple needs:

- 22% due to incontinence, of whom 80% also have an identified mental health need.
- 42% have a history of falls.
- 56% have cognition and memory problems.
- 35% have challenging behaviour.
- 26% of referrals for long term admission are due to carer breakdown. However 42% of respite referrals are due to carer breakdown with the case being re-presented within 4 to 6 weeks for a long term care admission often on a new basis. Of these:
 - 48% related to the spouse/partner not able to continue to support because of their own health problems or increasing age;
 - 37% were due to a daughter/son not being able to continue due to work or their own ageing.

the dementia service model.....

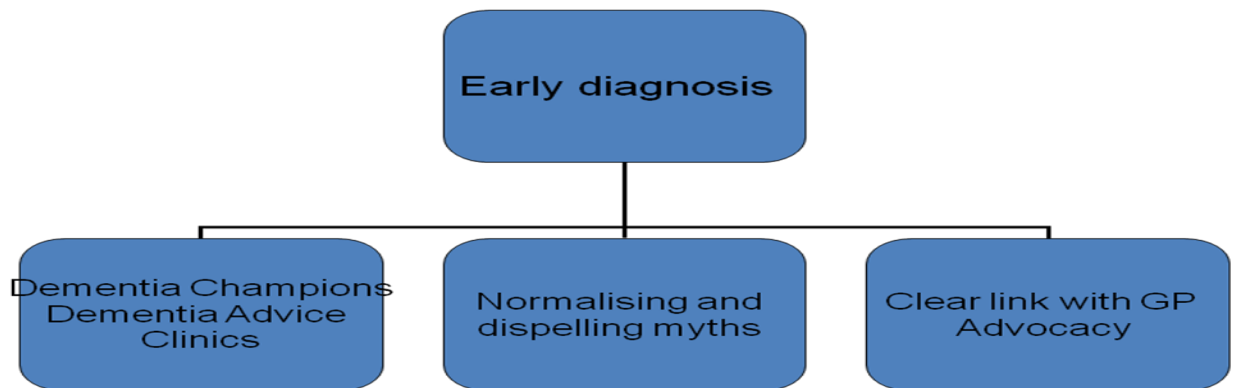
Like most social and health care services, dementia care consists of a number of different elements in a system. The dementia pathway describes the current system. There should be:

- An integrated approach to support and care services
- Co-ordination between care, support and medical services.
- A co-ordinated Public Health approach –

We looked at three distinct aspects of the care model

early diagnosis.....

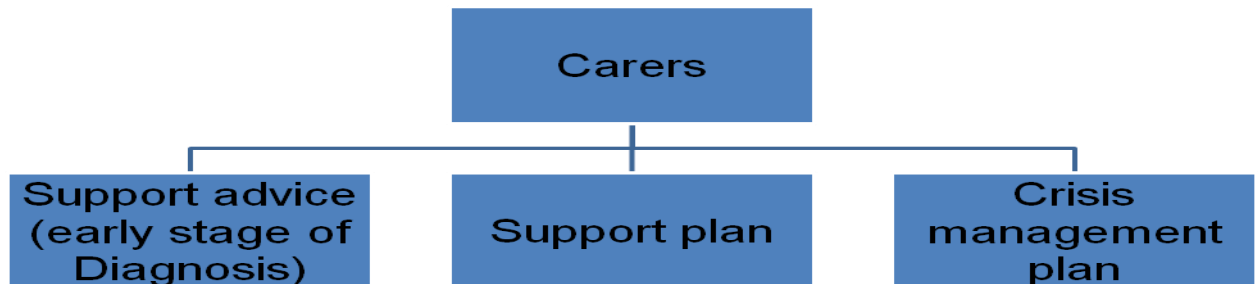
- Early diagnosis by GP's appears inconsistent –how we can improve this so people who have concerns about their memory can access services and gain advice for themselves and their carers a long time before they reach a crisis point?
- Support for carers – this is key to supporting people with dementia in the community and avoiding unnecessary longer stays in hospital
- Hospital stay – findings highlighted that people with dementia can often face longer hospital stays as a result of not having appropriate care/support packages in place when their medical condition has been treated. This is expensive and not in the person's best interests.
- Early diagnosis is key to ensuring correct support packages are provided at the onset. These will involve key professionals and pivotal to this is the carer.
- Health centres & GP surgeries should have dementia clinics supported by a dementia champion in each practice
- The aim should be to provide an informal setting for people who have concerns about their memory to obtain advice and information and undertake a basic memory test. The champion will also normalise the condition and help alleviate the stigma that surrounds dementia by dispelling myths etc.
- This will provide a clear link to the GP as, if required, the champion can act as an advocate for the patient.
- We recognise that there will be a cost in developing this service, however we feel that this cost is justified as it will prevent people from accessing GP's and other services in crisis, which may result in hospitalisation. It also mirrors other screening services that work on reducing the impact of illness by early diagnosis, therefore creating savings. It also reflects government proposals on dementia.



Support to carers.....

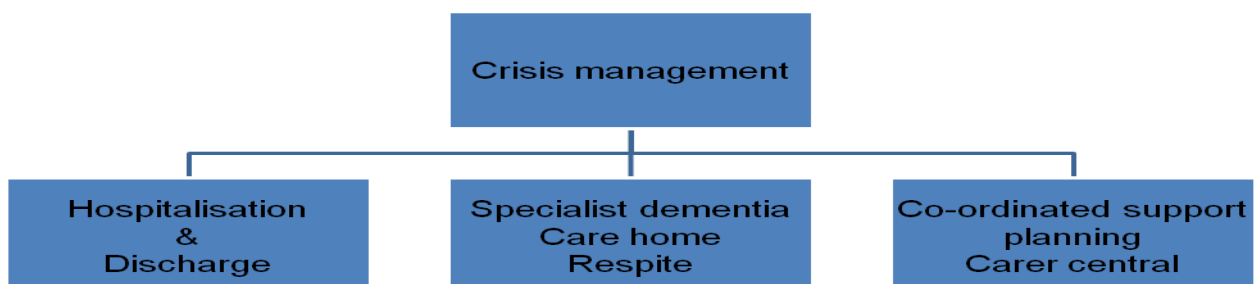
- After assessing all the information collated from our review, it was clear to us that a more integrated approach should be adopted by all agencies and that a revised Dementia Strategy should be developed to deliver this.
- The approach would ensure that co-ordination and communication occurred between health and social care professionals and was relayed to the carer.
- Calderdale should seek to become a dementia friendly borough, following the examples of York and Sheffield.
- Carers are pivotal to this as they provide support and care and are often the link/advocate with health and social care professionals.
- We would like to see the specific issues about caring for people with dementia included in the carers' strategy.
- The carer or potential carer should - at the point of diagnosis (the earlier the better!) be provided with a support plan that highlights what to look for and how to support their partner/relative/friend etc. It should also include contact numbers and support groups etc.
- Along with this a crisis management plan must be made available for a carer to know what to do when there are problems either for the person with dementia or their carer.
- Where there is a hospital admission or a respite stay the plan must be developed to meet all circumstances and be developed using a socio-medical model. The carer should be a key player in the development of this as they will be providing the care and support on a daily, often 24 hour basis.

- Again the aim is to support people with dementia at home and reduce risks by equipping the carer with the skills and planning for potential crisis.



health and formal care.....

- We recognise that on occasion, despite best efforts, people will require hospital treatment and admission. However we are also mindful that more often than not people experience an extended stay in hospital whilst respite care is accessed. This can have a detrimental affect on the person with dementia and may also block hospital beds and be costly.
- We would like to see a commitment to purchase a crisis bed at a specialist dementia care home which can be accessed by a person once the medical ailment has been treated. This will reduce unnecessary hospital stay, free up beds and support the mental health and well-being of the dementia sufferer as their dementia needs will be cared for within a specialist setting.
- This crisis bed space can also be available for someone where a carer requires emergency attention that cannot be planned for. Co-ordinated specialist planning is crucial to this.



courageous commissioning.....

Much as we would like to, we are not calling for additional resources for dementia care, except where there is a clear *invest to save* argument. The economic climate means that all services have to expect to work within reduced financial resources.

We do, however, think that 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. There may be an element of *invest to save* required as the benefits from earlier diagnosis will take time to work through the system.

We also consider that additional resource should be identified for staff training within the general hospital to allow for more dementia champions to be identified and for expanding the innovative and successful Butterfly Scheme, where a butterfly emblem on a patient's bed identifies to ward staff that they have a dementia. We believe that this would have a significant impact on reducing hospital lengths of stay and inappropriate discharges to residential or nursing care.

Carers told us how much they valued the advice and support services provided by the Alzheimers' Society. Commissioners should consider including commissioning some support and advice services from voluntary and community sector organisations. Such organisations should be given sufficient certainty of funding that they are able to plan the delivery of services over several years. If necessary, funding arrangements should include supporting the infrastructure of community and voluntary organisations if that is necessary to leave them placed to provide advice and support services.

Recommendation 1

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.

In a recent study carried out in Nottingham, one hospital consultant said,

I just don't think I've ever, ever, ever in my entire training, had any teaching about how to look after people with dementia.

And, while this is an extreme example from the Nottingham study, it is indicative of a general concern about levels of dementia awareness. We have no reason to believe that the position should be substantially different in Calderdale.

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.

Recommendation 2:

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.

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. *Together for a dementia-friendly Bruges* is a successful example of how this can work.

The Joseph Rowntree Foundation is currently undertaking a piece of research '*Dementia without walls*', which aims to identify the factors that determine whether York is, or can become, a dementia-friendly city. Drawing on the engagement of local people who are living with dementia, it will make recommendations on how to overcome barriers to achieving this. The project seeks to raise the aspirations of people with dementia and their carers, as well as those of providers and commissioners, about what services in York could become, by identifying practical exemplars locally, nationally and internationally.

We would like to see Calderdale working towards becoming a dementia friendly borough and to learn the lessons from Bruges, and – nearer to home - York and Sheffield which have taken up this approach.

In Ripon and Harrogate businesses have signed up to support the National Dementia Declaration and Appleton's, a local butcher's shop, were one of the first to sign up. The owner, Anthony Stern said,

We have been overwhelmed by the way in which our staff have embraced the declaration and by taking some very simple steps, such as providing a quiet area in the shop where staff can take the time to offer dementia friendly service, Appleton's has been able to make significant improvements to the level of service our customers receive.

There have been some recent national campaigns raising awareness of dementia and we heard some evidence that this has resulted in increased numbers of people seeing their GP and accessing other services with concerns about their memory.

One GP commented to us:

Expectations of [the] public exceed what can be offered / provided. Media adverts etc give unrealistic and ill-informed expectations

We don't accept this view. People with dementia have a right to access services and awareness-raising campaigns help people be aware that they have a problem and can seek help. Successful campaigns will shift the balance of service access, which is why we recommend that significant resources should move from secondary care and residential settings to further upstream in the system, and, in particular, to primary care.

Recommendation 3:

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

Margaret and Edward Hever 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.

a visit to the doctors...

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:

Currently 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. Further, diagnoses are often made at a time of crisis; a crisis that could potentially have been avoided if diagnosis had been made earlier. A core aim of the National Dementia Strategy is therefore to ensure that effective services for early diagnosis and intervention are available for all on a nationwide basis. There is evidence that such services are cost effective, but will require extra initial local investment to be established. When established, such services can release substantial funds back into health and social care systems.

Some of the carers we spoke to were not satisfied with the service they received when they first visited their GP. They felt that, sometimes, they were not directed to broader advice services when a diagnosis of dementia was made.

On the other hand, GPs told us that services they wanted for their patients were not always available, or took too long to be delivered. One said:

There can be a delay of weeks between referral to memory service and diagnosis. This in turn leads to a delay in support by CMHT (Community Mental Health Team)

And another commented,

Very slow to get through various stages of diagnosis – scan, interpretation, initialising treatment getting support in place. Patient's condition often greatly deteriorated before progress from point of referral made.

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.

The Alzheimers' Society stressed to us that early diagnosis allows the person with dementia a much bigger say in their future, rather than when their condition has deteriorated and they are much less able to participate in important decisions about their life. Advice and planning at this stage mean that carers, in particular, are better prepared for a crisis when it arrives. Apart from the benefits for the family, this often reduces or delays the need for costly state intervention.

It is a key recommendation of this report that primary care is recognised as the key entry point to the “dementia care system” and that primary care services are 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.

A good example is the Gnosall surgery in Staffordshire, that *developed a primary care memory service for its 8,000 patients that dramatically reduced hospital costs. Two questions about memory were added to the checklist used on patients attending QOF (Quality and Outcomes Framework) clinics. Those with memory concerns were visited at home by a health visitor, to carry out checks for dementia and depression, and to arrange blood and urine tests. GPs were detecting on average 40% of dementia cases and referring them to secondary care. Now about a third of the patients visited are diagnosed with dementia.*

Recommendation 4:

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

Recommendation 5:

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.

Recommendation 6:

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.

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."

carers as the main care providers....

Family carers form the largest part of the support systems available to people with dementia and, as the population of people with dementia grows, the number of people fulfilling a caring role will grow too.

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 Adults Health and Social Care Scrutiny Panel is contributing a review of the Carers' Strategy as part of another piece of work and we will make sure that the revised strategy pays particular attention to the needs of carers with dementia.

All our recommendations in this report are driven by the needs of people with dementia and their carers, so we do not feel the need for separate recommendations about carers, except that the Carers' Strategy should make particular reference to dementia, so that the Council, the NHS and other partner organisations make sure that they listen to carers, not just when they are discussing the needs of their family member, but when they are planning to commission new services, decommission existing services or are reviewing the quality of services.

Recommendation 7:

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

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.

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."

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 care that they receive in hospital should be altered to take account of their dementia – and we heard many examples of how this is happening. The Nurse Consultant for Older People at Calderdale Royal Hospital told us...

We have extended the length of time people with dementia spend in the Medical Assessment Unit. Normally the target is that people should not stay longer than 24 hours, but this is extended to 48 hours when a person has dementia. This gives more time to assess and identify a package of care.

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 hospital.

The new post of Dementia Matron at the hospital has provided an invaluable specialist resource that has provided invaluable support to other professionals in the hospital and has contributed to reducing lengths of stay for patients.

An evaluation report into the role of the Dementia Matron quoted a hospital colleague...

We did not know about the dementia matron. We were having great difficulty organising patient's future care. Out of the blue a dementia matron arrived one day unannounced. From when she got here she was very helpful and the patient was discharged soon after. We could have done with the support from the outset.

But the same report quotes a relative as saying...

Until I told the nurse on the ward that my father had dementia (which should have been in his notes) when he was due to be discharged the dementia matron had not been involved at all. The nurses were kind but I felt that the actual discharge was not thought through as my father would have been discharged to an empty house and he didn't even have a key. Luckily the dementia matron got involved.

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 that ward staff sometimes tend to take the risk-averse and more comfortable route discharging patients to residential or nursing care, rather than seeking to make the arrangements for the patient to go home. This can get people “locked into” the formal care system to the detriment of their quality of life and at high cost to the state.

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 National Audit of Dementia Care in General Hospitals 2011 made a series of recommendations addressed predominantly to acute hospital trusts, but also to other agencies. These recommendations provide a useful checklist that dementia issues are being addressed in general hospitals and we have arranged for a discussion with the Calderdale and Huddersfield NHS Foundation Trust about their response to the recommendations.

Recommendation 8:

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

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*

Recommendation 9:

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.

Recommendation 10

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.

Recommendation 11

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.

Recommendation 12:

The recommendations of the National Audit of Dementia Care in General Hospitals 2011 should be implemented in full and progress reported in the Quality Account.

what next for scrutiny....

This report is a stage in the Adults Health and Social Care Scrutiny Panel's work on dementia, not the end of it.

We have already asked the Council and NHS Trusts to meet with us to discuss how they intend to develop services to people with dementia through their business planning process for 2012/13 and that meeting took place in April 2012.

Over the coming months we will be considering the revised Carers' Strategy and we will pay particular attention to what it has to say about support to carers of people with dementia.

The Scrutiny Panel has been successful in being identified as one of fifteen Scrutiny Development Areas in the country. Our project will use this review as a springboard to us developing strong and effective partnerships to make sure that proactive overview and scrutiny can continue and develop under the new health service arrangements, so that overview and scrutiny is the fundamental way that Councillors voice the views of their constituents about health and wellbeing and hold services to account. This gives us a great opportunity to work with all parts of the health and social care system on taking these recommendations forward.

We wish to see rapid progress on introducing improvements to services for people with dementia and we so we will revisit the recommendations in this report in November 2012. We would like to see that some new approaches have been tried out and, where it has not been possible to change commissioning plans for 2012/13 that good progress has been made towards a new approach for 2013/14.

Finally – and perhaps most importantly – we will consider whether the needs of people with dementia have been considered in all reports we receive and we will also keep an eye on reports submitted to other Scrutiny Panels and Cabinet where there may be an impact on people with dementia.

In order to keep this report concise and to focus on our findings, we have not included details of our evidence gathering sessions in this report. If you are interested in this detail, or have any other enquiries, please contact Scrutiny Support, Democratic and Partnership Services, Room 23, Town Hall, Crossley Street, Halifax, HX1 1PS
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