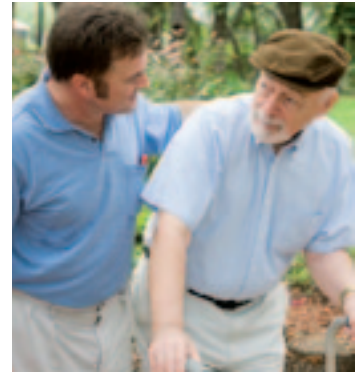
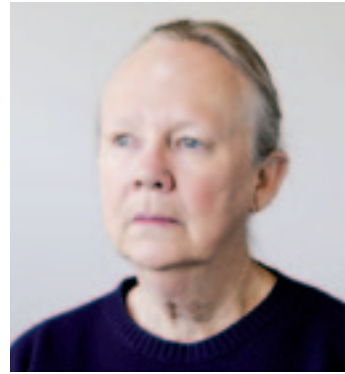




Living Well With Dementia: A Strategy for Worcestershire 2011 - 2016

Executive Summary - June 2011



Living Well with Dementia

In order to achieve the aims of the national dementia strategy and meet the local demographic challenges facing the county it is imperative that health and social care services, in partnership with other services, have a clear strategy for supporting people living with dementia, their families and carers in Worcestershire, now and in the future.

The delivery of health and social care services are facing radical changes following the publication of the NHS White Paper in July 2010 and the Comprehensive Spending Review 2010 - 2014. One thing that will remain unchanged locally is our commitment to keep dementia care as one of our top priorities.

This changing context at both national and local level requires us to prepare a strategy, which in uncertain times, sets out a clear vision underpinned by health and social care's commitment to dementia. This vision acknowledges the evident and sometimes unpredictable challenges concerning finance and the changing population which makes planning and implementation locally more complex.

We feel that our local strategy will meet these challenges, embracing a wider society approach to dementia, building on established work programmes and aiming to deliver improved quality of care and health outcomes for people living with dementia, recognising the contributions of informal carers and the workforce.

Indeed the new Government's core policy themes of localism and Big Society, personalised care and support, care closer to home, and 'no decision about me, without me' underpin the local development and delivery of this strategy through community engagement and integration.

In order to meet the varied needs of people living with dementia it is vital that a wide range of services are engaged in the delivery of care and support. For this reason the strategy is based on a shared vision amongst all key agencies across the sectors and a collaborative approach towards the delivery of joined up services.

In particular we feel the development of services that support people to 'live well with dementia' within the community following early diagnosis and subsequent delivery of information advice and emotional or practical support should be at the heart of the strategy and are the key to success.

This ethos will inform decisions on how resources are allocated in the future with regard to support services for people living with dementia. This will also influence the practice of a wide range of service providers with regard to their understanding and awareness of dementia and their subsequent delivery of effective support services that are person centred.

We are extremely pleased to release this strategy. Its implementation will drive forward the development of important changes in the delivery of support services for people with dementia and result in improved care and quality of life for people living with dementia, their families and carers across the county.

What is Dementia?

Dementia is a progressive terminal brain disease characterised by a gradual loss of mental awareness, loss of memory, personality change and deteriorating and debilitating functional capacity. It is characterised by varying mental health and physical symptoms and often requires complex care.

For most people the cause is unknown but there are some known causes or risk factors such as:

- Diseases and infections that affect the brain e.g. Alzheimer's disease or meningitis
- Pressure on the brain e.g. Brain tumour
- Lack of blood and oxygen supply to the brain e.g. Stroke and head injuries
- Cardiovascular insufficiencies.

Dementia is most common in people over the age of 65 but there are also a smaller cohort of people who develop 'young onset' or 'working age' dementia from as young as 35.

Most dementia's are permanent and since deterioration is gradual the diagnosis is often delayed and treatment options therefore reduced. There is clear evidence that the earlier into the disease that dementia is diagnosed the better the outcomes for those with the illness and their informal carers, it will help with decision making and preparing the individual and their family for choices they will need to make in the future.

There is no evidence that dementia can be prevented specifically, however dementia risk is highlighted in the National Strategy for heart disease, stroke and hypertension. Risks can be reduced by improved lifestyles such as weight loss, limited intake of alcohol, health checks and heart MOTs; what is "good for the heart is good for the brain".

Incidence

It is estimated that there are 750,000 people living with dementia in the UK and that this figure will rise to over 1 million by 2025.

Incidence equates to about 6 in 100 people aged over 65 developing the condition, rising to around 20 in 100 for people aged 85 or over. Young onset dementia is rarer with only around 1 in 1,000 people under 65 affected (Dementia UK 2007).

The incidence of dementia increases in certain groups, in particular individuals with learning disabilities. The symptoms of dementia vary but the frustrations and confusion associated with these can lead to distress and aggression, even in people who previously never exhibited such behaviours. This can make caring for people with dementia very challenging.

It is estimated that the current financial cost of people living with dementia in the UK is over £20 billion a year, and as such that its financial impact is more than that of cancer, stroke and heart disease combined.

In Worcestershire, the number of people with dementia is proportionately higher than in other areas of the country, and these numbers are projected to increase considerably over the next 15 years as people live longer.

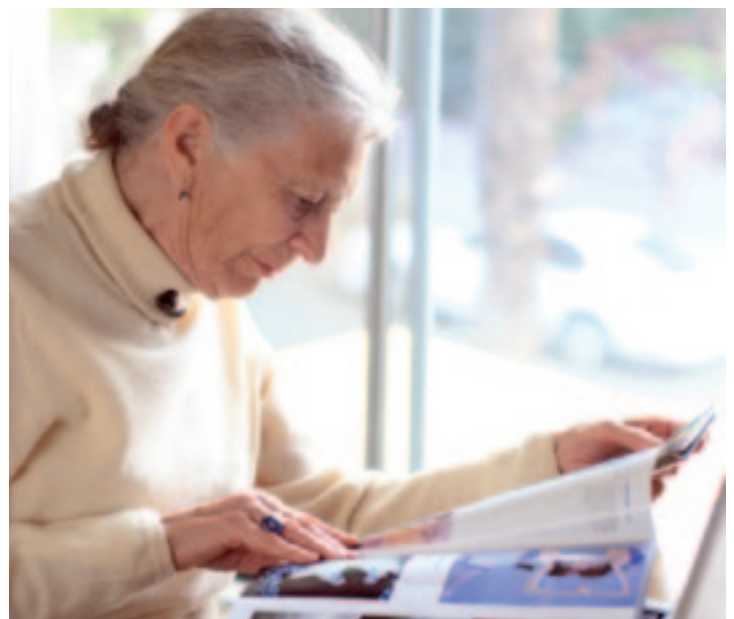
Local Services

In order to develop our dementia services appropriately, local service reviews and service mapping have been undertaken and have indicated essential areas for future work:

- Public and professional awareness and understanding of dementia
- Access to early diagnosis
- Dementia support services across the pathway
- Carer support
- Care/Nursing Homes
- GP/Primary Care
- Acute Services.

These will include key themes that will underpin the delivery of this strategy, and we will ensure these are central to all that we implement:

- Workforce development to ensure our staff are understanding of the needs of those living with dementia and their families and carers, and have the skills to deliver person centred care
- Individuals with lived experience, family and carer involvement as partners in the development and implementation of the strategy
- Data and system modelling to underpin the appropriate development of services
- Services that respond to equality and diversity
- Effective monitoring and evaluation of the impact of the strategy.



Aims of this Strategy

The vision for our strategy is informed by the vision in 'It's Really Time to do Something Now!' released by the West Midlands Strategic Health Authority in 2008.

Our vision is that:

"By 2016, all people in Worcestershire with a suspected or confirmed diagnosis of dementia will access integrated, seamless, proactive and high quality person-centred services that encompass all the expertise required to meet the needs of people living with dementia and those of their carers."

To deliver this vision our strategic aims are to:

- Raise public awareness and understanding of dementia – in order to demystify and reduce the fear associated with the condition
- Maximise the number of people with access to early diagnosis – to enable people to plan for their care and support needs as the disease progresses
- Develop key dementia support services with adequate resources – to ensure that people with dementia receive appropriate support at all stages of their condition
- Develop the understanding and skills of the workforce supporting people living with dementia – to ensure a common understanding of person centred care underpins the delivery of all services, recognising and prioritising individuality and placing humanity and compassion at the core of all service delivery.

The Department of Health's revised, outcomes focused implementation plan 2010/11 for 'Living Well with Dementia' highlights 10 Quality outcome statements for people with dementia. These are:

1. I was diagnosed early
2. I understand, so I make good decisions and provide for future decision making
3. I get the treatment and support which are best for my dementia, and my life
4. Those around me and looking after me are well supported
5. I am treated with dignity and respect
6. I know what I can do to help myself and who else can help me
7. I can enjoy life
8. I feel part of a community and I'm inspired to give something back
9. I am confident my end of life wishes will be respected
10. I can expect a good death.

Priority Areas

1. Primary Care (General Practice)

The provision of appropriate care through General Practice is essential to supporting the effective recognition and diagnosis of dementia and timely access to services.

Therefore we will:

- Develop a consistent approach to assessment in primary care
- Support the education and training of general practitioners and wider primary care teams regarding dementia and person-centred care
- Ensure appropriate and consistent coding for dementia.

2. Public and Professional Awareness

People with dementia currently wait up to three years before reporting symptoms to their doctor.

In order to redress this we will:

- Strengthen the preventative and early intervention services targeting those people at higher risk of developing dementia
- Develop information for people living with dementia, their families and carers on the nature and impact of the condition and what support is available
- Enhance training for health and social care staff in the statutory, private and voluntary sectors
- Undertake a local public awareness campaign to challenge stereotypes and improve understanding of the signs and symptoms of dementia in order that people access services for diagnosis, treatment and support
- Ensure a voice for people living with dementia, their families and carers in the development of future services.

3. Information and Signposting

At present access to and the quality of information and advice related to dementia is limited within the county.

Therefore, we will:

- Develop targeting information to raise awareness of preventative and early intervention services
- Develop accessible information through existing and new services, for people with dementia, their families and carers on the nature and impact of the condition and what support is available
- Ensure that key health and social care staff are able to offer appropriate advice or know where to signpost people with dementia, their families and carers at suitable points in their care pathway
- Post evaluation of the Dementia Advisor Service review the future position of these roles in the pathway and increase access to these services
- Develop a central point of contact for information and signposting.

4. Peer Support and Learning Networks

We know that there is real potential for people with dementia, their families and carers to benefit from peer support. Peer support allows people living with dementia and their carers to meet with others in the same situation and gain an understanding of how others cope and the problems they encounter.

Therefore we will:

- Explore the development of current and new models of peer support to increase access to this across the county for the increasing numbers of people with dementia who will be diagnosed as a result of actions arising from this strategy.

5. Workforce Development

It is recognised that many key health care and social care staff, whether in the statutory, private or voluntary sectors, lack suitable understanding of dementia and the skills or approach required to deliver high quality person centred care.

Therefore we will:

- Develop and deliver during 2011-13 a workforce training programme for all key health and social care staff in the statutory, private and voluntary sectors that equips them with the appropriate understanding, skills and knowledge to deliver person centred dementia care and support
- Develop and roll out a training DVD and handbook to sustain the gains of this training programme
- Evaluate the impact of this training from the point of view of staff participating but more importantly from the view point of people with dementia, their families and carers, with regard to the quality and effectiveness of the care and support received
- Develop a culture of care practice within all key health and social care services where 'feelings matter most' and where those with dementia are recognised as individuals with unique and personal needs
- Value our workforce and treat them with dignity and respect.

6. Supporting Families and Carers

Families and carers are the major source of care and support for people with dementia in the community, and we need to support them to continue providing that care and support through the progressive journey with dementia while recognising their needs for a life of their own.

Therefore we will:

- Ensure that the involvement of families and carers is recognised through training by health and social care professionals and acted upon at all stages in the care and support of people living with dementia
- Explore the development of enhanced information, advice and support services for families and carers
- Formally engage NHS Trusts in support of the Carers Charter, supporting carers with dignity and respect
- Support families and carers with dignity and respect.

7. Early Diagnosis and Intervention

Locally it is estimated that only one-third of the people with dementia in the county have been identified and have a formal diagnosis; Yet we know that the later you receive a diagnosis the harder it is to support those with dementia and their carers to manage the illness and make informed choices about how they want to live.

Therefore we will:

- Ensure that all people with suspected dementia are professionally assessed and receive a full diagnosis and information support from the new Early Intervention and Diagnoses Service in order that they can be aware of and access appropriate care and support
- Explore the potential expansion of Dementia Advisers to the whole county.

8. Social Care and Support at Home

Our priority is for the care and support of people with dementia in their own home rather than in an institutional care setting.

Therefore we will:

- Engage all key health and social care staff concerned with delivery of home based services in the workforce training programme
- Ensure that all key health and social care staff develop care and support packages that aim to prevent admission of patients to acute hospital services and care homes
- Agree a system for the shifting of resources from acute hospitals to community based health, care and support services, based on the number of prevented admissions
- Ensure that intermediate care services allocate sufficient time to the re-ablement of people with dementia
- Improve joint working between dedicated home based services that specialise in the care and support of people with dementia, dedicated dementia care and support.

9. Support in the Community

At present support for people with dementia, their families, and carers in the community is relatively limited. There are issues of inequity of support across the county and these services are reliant on external funding from specific grants.

Therefore, we will:

- Explore the potential expansion of support across the county
- Continue to work closely with the Alzheimer's Society to support existing services and invested in a county wide dementia café project to pump prime the development of peer support groups to cover the gaps in county provision
- Build capacity in the voluntary and community sector through established grants/networks
- Up skill the workforce amongst key organisations such as Age Concern
- Develop opportunities for meaningful day activities.

10. Care Homes and Supported Housing

The needs of people with dementia and their carers should be integral to the development and delivery of supported housing schemes and developments in care homes. As with other health and social care staff those working in these settings need the understanding and skills to deliver person centred care.

Therefore, we will:

- Support care homes to reduce the use of anti-psychotic drugs
- Support families and carers to better navigate the system
- Ensure that future supported housing and extra housing strategies clarify the importance of supporting people with dementia within mainstream schemes
- Deliver a training programme for staff working in supported housing schemes and care homes that provide them with the skills and understanding to deliver person centred care
- Continue the assessment of care homes in 2011/12 and 2012/13 against the local dementia standard to ensure we have a large number of care homes in the county that meet our requirements for future placements.

11. Crisis and Respite Care

In order to prevent or reduce the number and frequency of admissions to hospital or urgent respite care as a result of either carer breakdown, or a crisis of care for the person with dementia, we need to focus on effective advance planning.

Therefore we will:

- Embed emergency or contingency planning into the development of care and support plans for people with dementia and their carers as part of the service provided by the Early Intervention and Diagnosis Service and Dementia Advisers
- Develop alternative options for people living with dementia.

12. Specialist and Mental Health Services

Worcestershire Mental Health Partnership Trust is undertaking the modernisation of older adult mental health services across the county. The focus is around providing care and support in the most appropriate way and enhancing the provision for specialist dementia care.

Therefore, we will:

- Progress the planned modernisation of the older adult mental health services to ensure that the above objectives are met so that specialist services can complement the more generic development of health and social care services across the county.

13. Medicines Management

In Worcestershire most districts have seen an increase in prescribing of drugs over the last four years. However it must be noted that pharmacological treatment in the West Midlands is the lowest across the country.

The national guidance is to restrict the use of drugs to situations where it is required and to reduce their use to address distressed behaviour.

Therefore, we will:

- Audit practice to establish definitive prescribing figures
- Ensure all people with a diagnosis of dementia have access to the appropriate anti-dementia drugs and all medication appropriate to diagnosed conditions is available
- Ensure all dementia care staff are involved in and have access to training in medicines management, so that those prescribed medication receive it at the appropriate time
- Ensure medicines management, including regular medicines reviews and medication concordance discussion by appropriately trained individuals are fully included in individual care plans for people with dementia
- Measure the use of anti psychotic medication in people with a dementia diagnosis in the community, care homes & NHS specialist units with 3 monthly reviews
- Develop guidance on the administration of anti-psychotics.

14. Hospital Care

The majority of hospital patients on acute medical wards with dementia do not have a formal diagnosis and are not known to specialist mental health services. This is significant because hospitals are challenging environments for people with dementia and can result in poor quality of life and what is perceived to be resultant challenging behaviour.

As a result people with dementia tend to spend longer in hospital than other patients and account for a high proportion of all patients with delayed discharges.

Therefore we will:

- Build on the intelligence gathered from a recent audit of practice in the local acute hospitals to develop a pathway from access to discharge, which ensures that the dementia diagnosis is not the cause of prolonged stay
- Deliver dementia care training to key hospital staff in acute and community settings to enhance their understanding and skills to support people with dementia
- Include the Promoting Independence Service, Intermediate Care Teams and Community Hospital staff in delivery of the dementia care training programme to enhance their understanding and skills to support people with dementia and maximise alternatives to admissions as appropriate.

15. End of Life

Making plans for the end of one's life is a major issue for people with dementia since their illness results in loss of mental capacity and the subsequent ability to make decisions about this area of their life.

With improved access to early diagnosis we will be able to support people with dementia and their carers to plan ahead and avoid having to make crisis decisions that result in hospital admissions.

Therefore, we will:

- Train care home and home care staff in the Gold Standard framework for end of life care to ensure that they can provide high quality support in those settings and prevent people going into hospital
- Explore the training of staff working in palliative care to ensure they have the required understanding and skills to provide good quality care and support for people with dementia.

16. Young Onset Dementia

Dementia has long been associated with the inevitable ageing process yet significant numbers of people develop the condition under the age of 65. In Worcestershire it is estimated that there are 160 people with young onset dementia.

The availability of services for people with young onset dementia is limited. In particular there is a lack of age-appropriate respite and rehabilitation services as well as longer term residential care.

Therefore, we will:

- Build into the specification for dementia services the requirement to work appropriately with people with young onset dementia
- Increase investment into young onset dementia support services to increase capacity
- Build into the training programme for key health and social care staff the need to understand the specific issues related to young onset dementia.

17. Dementia and People with Learning Disabilities

Nationally, about 20 per cent of people with a learning disability have Down's syndrome, and people with Down's syndrome are at particular risk of developing dementia. The prevalence of dementia in other forms of learning disabilities is approximately four times higher than the general population (Cooper 1997, Lund 1985, Moss and Patel 1993).

Therefore, we will:

- Build into the specification for dementia services the requirement to work with people with learning disabilities in a way which supports their special needs
- Build into the training programme for key health and social care staff the need to understand the specific issues related to people with learning disabilities who develop dementia.

18. Dementia in Prison

A recent local needs assessment highlighted that the incidence of dementia in prisons was much higher than expected given the age range and numbers involved, with very high rates of young onset dementia identified.

Therefore, we will:

- Work with Prison Healthcare commissioners to raise the standard of dementia care in prisons, linking to the Workforce Development Programme and local Dementia Care Standards in Care Homes as appropriate.

19. Equality and Diversity

Although we currently lack data on dementia within ethnic and other minority communities, for example, sensory impairment, across the county, we do know that both the incidence of dementia and the potential needs of communities differ.

Therefore, we will:

- Establish data regarding equality and diversity and dementia
- Ensure there is a better understanding of the social and cultural needs of minority communities in the county
- Ensure training to provide a greater awareness of the needs of minority communities
- Monitor access to dementia services to ensure they are meeting the needs of minority communities.

20. Safeguarding

People with dementia are known to be an 'at risk' group in terms of abuse, particularly financial exploitation and neglect. Reliance on others for support to manage finances or intimate care can expose people with dementia to an increased risk of abuse.

Therefore we will:

- Embed a safeguarding culture into the development and delivery of all dementia services through training and information on local arrangements for reporting concerns.

Summary

Transforming the quality of dementia care in Worcestershire is a huge challenge for all aspects of the health and social care system and the wider community. People living with dementia, their families and carers, the wider public and professionals in health and social care all have their part to play in achieving this transformation and meeting the aims and outcomes of this strategy.

The rising projections for dementia prevalence will continue to be Worcestershire's major concern, and it is a crucial that we create a sustainable support system for people living with dementia across our local health and social care economy. To deliver the strategy in full we need to implement it in a co-ordinated and joined up manner across the dementia pathway to ensure success.

Ten Principles of Care

Dignity in Care Means

1. A zero tolerance of all forms of abuse
2. Supporting people with the same respect we would afford ourselves or our family members
3. Treat each person as an individual by offering a personalised service
4. Enabling people to maintain the maximum possible level of independence, choice, and control
5. Listening and supporting people to express their needs and wants
6. Respecting people's right to privacy
7. Ensuring people feel able to complain without fear of retribution
8. Engaging with family members and carers and care partners
9. Assisting people to maintain confidence and a positive self-esteem
10. Acting to alleviate people's loneliness and isolation

Dignity at the heart of everything we do

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