Living well with dementia

Transforming the quality and experience of dementia care for the people of Suffolk

A collaboration between Suffolk County Council, NHS Suffolk and Great Yarmouth & Waveney
Transforming the quality and experience of dementia care for the people of Suffolk
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FOREWORD

Dementia is wreathed in stigma, misunderstood and often not diagnosed quickly enough, leaving individuals with dementia, their families and carers in difficult circumstances.

The number of people living in Suffolk affected by dementia is set to rise by 65% for those aged 65 and over – from 9,870 people in 2008 to an expected 16,327 people in 2025. Over the same time, there will be a rise from 199 to 232 of those people aged between 30 and 64 diagnosed with dementia.

In Suffolk we have consulted widely with people, including family carers, over several months to understand the current picture, what is needed and what will best work in achieving the aims of the strategy.

Using that valuable feedback, NHS Suffolk, NHS Great Yarmouth and Waveney and Suffolk County Council have jointly developed and agreed this strategy to transform the quality and experience of dementia care for the people of Suffolk. It will be important for all those affected in Suffolk, whether it be those who develop dementia themselves, or family carers who do such a valiant job caring for and supporting loved ones.

It is underpinned by the National Dementia Strategy, which focuses on three themes: raised awareness and understanding of dementia; early diagnosis and support: and giving people the ability to live well with dementia. The national strategy encourages development of good practice to lead decisions how to provide the best possible care for people, which we intend to stick to.

Our strategy, using what we have called the Suffolk Perspective, aims to raise awareness, make sure people are diagnosed earlier and have services to help them cope, while raising the standards of care. To minimise the impact of dementia on so many people’s lives needs a coherent, co-ordinated approach that embraces all services, both within the statutory and the third sectors.

By pulling together we can – and will - transform the quality and experience of dementia care for the people of Suffolk. In order to transform our commitments into reality this strategy will inevitably need to be a “living document”. The National Strategy relies on the development of good practice as a precursor to further developments and investment decisions. We will be developing and reviewing an Implementation Plan and Performance Management dimensions on the basis of progress locally and developments nationally.

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Transforming the quality and experience of dementia care for the people of Suffolk
PART 1 - WHERE ARE WE NOW?

It is a little known fact that much can be done to delay the onset and progression of dementia. Lifestyle changes, such as cutting down on alcohol, having a good diet and not smoking, can reduce the risk of an individual developing dementia in the future.

Dementia can be caused by a number of illnesses in which there is progressive decline in multiple areas of function, such as memory, reasoning, communication skills and the ability to carry out daily activities. Behavioural and psychological symptoms are not uncommon, such as depression, psychosis, aggression and wandering.

Dementia is a long term terminal condition that impacts on a person’s health, social circumstances and family life and has accordingly been given specialist consideration in long-term commissioning strategies.

The risk factors for dementia are complex and vary according to the type of dementia. However, there is a higher risk of dementia:

- With age - about one in 14 people over 65 and one in six people over 80 has some form of dementia.
- In women - who are slightly more likely to develop dementia than men.
- In smokers.
- In those who consume alcohol to excess.
- With an unhealthy diet.
- In obesity and in those who do little physical exercise.
- If the mind is not kept active.

OVERVIEW

The purpose of this joint five year strategy for Suffolk is to ensure that the commissioning and provision of services for people with dementia and their families are: comprehensive, centred on the individual’s circumstances, clinically sound and are value for money. The National Dementia Strategy (DH 2009) clearly outlines the expectations the government has to ensure a better life in the future for all of those affected by dementia.

In Suffolk in excess of £35 million is currently being spent on people with dementia - although this figure is difficult to extract as a lot of people have multiple needs, and therefore many of their needs are met by a wide range of services.

A Joint Dementia Commissioning Board, made up of representatives from NHS Suffolk, Suffolk County Council and NHS Great Yarmouth and Waveney, the Mental Health Partnership Trusts and Supporting People was established to oversee the development of this strategy. It will mean we can ensure the people of Suffolk have the right services in place, at the right time and delivered to the correct standard. The strategy takes into account the National Dementia Strategy (DH2009), the Suffolk Joint Strategic Needs Assessment, Local Area Agreement, High Quality for All (DH 2008) and the NHS Next Stage Review. It has been influenced by a number of key national and local policies. The key influencing documents are referenced at appendix 1.
The Strategy has been written at a time when arrangements for local government in Suffolk are under review by the Boundary Committee, with a final outcome expected later in 2009.

Workshops have been held across the county as part of the feedback to the government on the initial draft assessment and latterly on the Suffolk Perspective developed as part of this strategy. It is acknowledged that there are already a range of services being delivered within the county for those with dementia as well as their families. The knowledge and experience of these services have directly influenced the long-term commissioning intentions outlined in this strategy.

The work has adopted and developed three key principles to this strategy:

• The improvement of awareness and understanding of dementia among the general public, health and care professionals, and employers thus allowing for self-management and prevention;
• Ensuring the condition is diagnosed as early as possible to allow for early intervention and management of the condition; and
• Delivering high quality of care and support for those with dementia and their carers.

Using these three basic principles will mean that:

• There is a raised profile for people with dementia and those that care for them, ensuring they are actively involved in the design and evaluation
• Dementia care will become everyone’s business and is then treated in line with long term conditions
• We proactively seek to minimise associated stigma
• We provide an integrated service that is jointly commissioned ensuring that we have equitable services that are local for local people.

A major factor to the success of this strategy will be how we provide appropriate services for people’s immediate need as well as the growing need. The impact of this condition is multi-faceted and far reaching. We wish to take a holistic approach that encompasses the social and medical aspects including employment, housing, support and treatment. It will therefore be necessary to move away from traditional thinking and delivery models in order to gain an organic model that will deliver for the future.

FUNDAMENTAL PRINCIPLES
The services must be;

Integrated
• The whole care system, clinical and social services, should be joined up to help people living with dementia and their family carers.

Patient/person centred
• The person with dementia, their family and carers should be the focal point of commissioning. See ‘Strengthening the Involvement of People with Dementia’ CSIP 2008.
• Care should be provided that is centred on the individual, not the environment in which it is provided.
• Promotes independence through the personalisation programme, assistive technology, housing and intermediate care

**Family orientated**
• An approach that works in partnership with, and takes account of, the needs of all family carers

**Recognition for ALL services**
• Full recognition given to the importance of third sector services and Suffolk commissioners will ensure that voluntary service providers achieve full cost recovery for the services provided.

**Housed well**
• Housing solutions should be flexible and promote choice and independence, including the registration of care homes

**Offering help and prevention**
• If there is a crisis, the service should be able to respond and, where possible, prevent problems cropping up in the first place

**Targeted**
• Commissioners will ensure that services find and target populations with a higher prevalence of developing dementia, for example, Coronary Heart Disease and alcohol related conditions.

**Knowledgeable workers**
• All areas of care and health should be aware of dementia and specialist practitioners must be available with the skills to manage younger people with dementia and people with learning disabilities and dementia.
• The ‘specialist’ whether they be registered professionals or trained staff must be able to provide suitable evidence of the knowledge they have in caring for this client group. They may be employed by a variety of agencies but are aligned together into a specialist service within given geographical areas.

**Enough workers**
• Commissioners need to make sure there are enough workers to cope with demand

**Equal**
• Services should not discriminate on the grounds of age, race, gender, disability, culture, faith or sexual orientation. (Recording of age and ethnicity of service users should be emphasised as an inherent part of all quality monitoring systems)
• Adherence to legislation on mental health, the Mental Health Act (2007), Mental Capacity Act (2005) and the Singles Equality Act (2008)
• Providers need to demonstrate how all services treat people with dignity and respect

**Meets national standards**
• Services must comply with national drivers
Demographics
According to the Eastern Region Public Health Observatory Report (ERPHO 2008), approximately 16% of the region’s population are aged 65 or over and 2% aged 85 or over, which is comparable to the national average (mid range). In the eastern region, rates for dementia, particularly in men, are ‘significantly worse’ than the national average. Reasons given for this are high prevalence, variations in clinical practice, differences in the quality of care in the community and differences in how dementia is recorded and counted.

Primary prevention
The risk factors are similar to those for coronary heart disease, stroke, diabetes and cancer. Recent National Institute of Clinical Excellence (NICE) guidance recommends middle-aged and older people should be assessed for vascular and other modifiable risk factors for dementia (for example, smoking, excessive alcohol consumption, obesity, diabetes, hypertension and raised cholesterol) and, if appropriate, treated.

Also NICE recommends that healthcare professionals working with people likely to have a genetic cause for their dementia should offer to refer them and their unaffected relatives for genetic counselling.

There is also some evidence that higher brain activity is important. People who have been to college or university or who keep mentally active seem to be less likely to develop dementia as they get older.

Healthy lifestyles
This strategy will dovetail with Transforming Suffolk: Suffolk’s Community Strategy 2008-2028’s ambitions to support people to pursue healthy lifestyles. It will also work with Healthy Ambitions Suffolk, a vision to make Suffolk the healthiest county by 2028 by focusing on preventative health. Public services and many voluntary sector organisations and businesses have pledged to align to this goal. Communities will have opportunities to actively work together to improve their health, life quality, and for skills development or retention. There will be opportunities for major campaigns to help individuals manage their own lifestyles and make choices which will help them to stay as healthy as possible.

Suffolk – current resources
As part of the preparation to inform this strategy a mapping exercise was undertaken to find out what we have already in Suffolk – see appendix 3. This is an evolving document and it is fully acknowledged that there are constant changes in the county and that we may have missed some information. We will build on this as we extend the work over the next five years. The mapping has proved to be difficult as many of the services provided to people with dementia do not specifically record dementia as part of the needs of the individual. We will compare the methodology used within Suffolk with the national sites as information becomes available and will learn from this.

Suffolk partners
In order to offer a comprehensive service that offers choice and individualised support, it will be necessary to develop the provider market for Suffolk. These will need to work together to deliver a cohesive Care Pathway that best supports the person with dementia and their carers.
It is clear that implementation, affordability and delivery of the pathway in the future is dependent on a fully integrated joint-commissioning approach that is monitored and evaluated. It is acknowledged that there will be a need to redefine and redistribute resources in line with the needs of the population. This will require non-traditional solutions being sought with the necessary risk management.

**Suffolk Pathway**

Service provision for people with dementia traditionally relies on people visiting their GP, and does not necessarily create links between medical and social/community services and support. The model also does not demonstrate the timescale that this process can take for some clients which is often very lengthy.

Our new Suffolk Perspective has been used throughout the document to demonstrate the outcomes we wish to achieve against each of the twelve in the Department of Health’s National Dementia Strategy key objectives. It is shown in detail in appendix 4. This new pathway was approved in principle, subject to consultation, by Suffolk’s Dementia Commissioning Board. The pathway was then tested through consultation with the Carers Reference Group and the Suffolk Dementia Reference Group.

Its thrust is to ensure that we are meeting the “personalisation” agenda, and that the aims of services support concepts of independence, choice and wellbeing and putting people first.
Dementia - along term condition model of care

It is recognised that an individual service user may ‘dip in and out’ of the various stages depending on the nature of the condition or the need to know more - this may span a period of several years.

**SERVICE**

- Health promotion
- Education & Information
- Healthy lifestyles
  - Early detection
  - Self-management
- Early diagnosis and intervention
- Specialist information, advice
- Support management, supported independent living
- Specialised information, support management & service provision, that either provides directly or underpins others to provide effectively - palliative care
- Terminal care

**MANAGEMENT**

- Joint data collection
- Information reporting
- Performance management
- Risk management
- Joint Commissioning and development
- Market development and management
- Review
- Workforce planning and development

Suffolk Dementia Long Term Conditions Model 2009

**Workforce development**

It is essential that we have a workforce development strategy to underpin this strategy. This will ensure that all staff working with people with dementia and their family carers have the necessary skills and knowledge to deliver the services required. The strategy has been developed in Part 3 on “How are We Going to Achieve This?” starting on page 23.
PART 2 - WHAT ARE WE GOING TO ACHIEVE FOR SUFFOLK PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS?

RAISING AWARENESS AND UNDERSTANDING

National Dementia Strategy Objective 1: Raise awareness

Improving public and professional awareness and the understanding of dementia

Public and professional awareness and understanding of dementia to be improved and the stigma associated with it addressed. This should inform individuals of the benefits of timely diagnosis and care, promote the prevention of dementia, and reduce social exclusion and discrimination. It should encourage behaviour a change in terms of appropriate help-seeking and help provision.

The Alzheimer’s Society has pointed out high levels of stigma and a lack of knowledge about dementia that means people are not diagnosed quickly enough. It means that they do not get access to services and treatment. While there are currently services in place to respond to the needs of people with dementia these are often ad hoc, uncoordinated and do not allow people the chance to manage and cope with the way that dementia affects them.

Suffolk Perspective

We were told:
“There is a high degree of stigma which leads to poor acceptance of those who have the illness” – a family carer
“People don’t want to know about dementia until it hits them in the face.....then its too late” – a family carer.

We will:
- Create campaigns to help prevent, delay and support people with dementia by -
  - using government literature.
  - distributing Alzheimer’s Society leaflets (see appendix 3).
  - commissioning Suffolk specific literature and communicating well to promote healthy living, giving advice to reassure, signpost services and useful contact numbers.
  - promote mental health.
  - plan and put into place publicity and communications campaign.
EARLY DIAGNOSIS AND SUPPORT

National Dementia Strategy Objective 2:
Good-quality early interventions for all
All people with dementia to have access to a pathway of care that delivers: a rapid and competent specialist assessment; and accurate diagnosis sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis. The system needs to have capacity to see all new cases of dementia in their area.

Between half and two thirds of people with dementia never have a confirmed diagnosis (Alzheimer’s Society, 2007). Often it is at a time of crisis that a person is diagnosed and by then it is very late for them to be able to make choices. A core aspect of the National Dementia Strategy is to ensure that effective services for early diagnosis and intervention are available for all.

Suffolk Perspective

We were told:
The role of “GPs are so important as often they are the gatekeepers to services and yet we had to see our GP several times before he would really listen.”

“There is a real concern in regard to having sufficient funding for not only diagnostic services but all aspects of dementia in Suffolk.”

“Once newly diagnosed people, need to gradually absorb what this means and then be able to gain advice and support as and when they need it, it also does not need to be from a registered professional but someone trained in dementia who will provide ongoing support.”

“This needs to be seen as everyone’s business not just that of specialist mental health teams and appropriate shared care should be available.”

We will:
• Create local, high standard, easily accessible services. The National Dementia Strategy is quite prescriptive in its recommendations.
• Commission new specialist services delivering early diagnosis and intervention. The service would need to be inclusive providing diagnostics to people of all ages and ethnic backgrounds.
• Ensure that people are able to hold onto their skills and develop new ones, drawing on the Community Learning Skills Development Service, independent sector, libraries, museums etc.
• Use other services such as Community Meals, Suffolk Fire and Carers Together or Homeshield to identify early signs of dementia.
EARLY DIAGNOSIS AND SUPPORT

National Dementia Strategy Objective 3: 
Good-quality information for those with diagnosed dementia and their carers
Providing people with dementia and their carers, with good-quality information on the illness and on the services available both at diagnosis and throughout the course of their care.

During our consultation a family carer said it was important “…not to have too much all at once as it’s overwhelming.” Once diagnosed, patients need to be well informed as to what to expect, and how to manage their care. Well-selected, easy to read literature is vital to assist the patient and their family carer to ‘live well’ once diagnosis has been confirmed. The government is expected to produce a version of the acclaimed document ‘Coping with Dementia - a practical handbook for carers’ published by Health Scotland.

National Dementia Strategy Objective 4: 
Enabling easy access to care, support and advice following diagnosis
A dementia adviser or support worker to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers.

Suffolk Perspective

We were told:
“Often the lack of ownership of the needs of this client group means they fall between services or cannot gain the assistance required at times of crisis.”
“The specialists don’t want to know as my husband’s needs aren’t currently ‘mental health’, the general staff can’t cope with dementia. Who do I turn to as the situation gets worse? I need to relate to someone who understands!”

We will:
• Secure nationally produced handbooks.
• Supply dementia support workers from a variety of providers to support and advise people, with a view to Department of Health’s best practice.
EARLY DIAGNOSIS AND SUPPORT

National Dementia Strategy Objective 5:
Development of structured peer support and learning networks

The establishment and maintenance of such networks will provide direct local peer support for people with dementia and their carers. This will enable people with dementia and their carers to take an active role in the development and prioritisation of local services.

People draw significant benefit from being able to share experiences, to exchange practical advice and emotional support. There are several good examples across the county of carer and cared for support groups mainly supplied by the third sector and several are funded through the Carers Grant or through one off funding.

The Dementia Café model highlighted in the National Dementia Strategy and the carers groups are really valued by the family carers and their relatives. They are established networks which can be further developed to provide wider geographical coverage. If the strategy succeeds in ensuring that early diagnosis of dementia becomes the norm, then this opens up the possibility for much greater levels of peer support and interaction. This is a way of empowering and enabling people to support each other in a safe way.
LIVING WELL WITH DEMENTIA

National Dementia Strategy Objective 6:
Improved community personal support services
Provision of an appropriate range of services to support people with dementia living at home and their carers. Access to flexible and reliable services, ranging from early intervention to specialist home care services, which are responsive to the personal needs and preferences of each individual and take account of their broader family circumstances. Accessible to people living alone or with carers, people who pay for their care privately, through personal budgets, or through local authority-arranged services.

Suffolk Perspective

We were told:
“Staff disempower people – my husband could do some basic things but he was never given enough time.”

“The staff were really good they cared and found out a lot about my father and kept it all written up next to his bed.”

“Staff come into my home and they are all different daily, mum doesn’t know them, they don’t know her. I have asked for continuity but it doesn’t happen she therefore gets even more muddled.”

“No one could cater form mum as she was Polish and as the disease progressed. She could not remember her English words.”

We will:
- Build on existing services providing care and support for people with dementia and their family carers to offer flexibility in order to retain skills and a quality of life.
- Improve domiciliary and home care services to take a more holistic view and to include night-sitting service.
- Improve availability and flexibility of short-break services for family carer and person with dementia.
- Develop new models of community based day care services, taking into account the needs of the family carer.
- Staff within day services will have specialist knowledge of dementia and how to care for people with complex needs.
- Increase and develop very sheltered housing and extra care housing.
- Improve availability and flexibility of short-break services. Services should either be bed-based, come to the customer’s home or aligned to day service provision.
- Improve on advocacy services.
- Explore befriending/peer support services to help people live independently at home.
- Safeguard people with dementia from abuse or becoming victims.
LIVING WELL WITH DEMENTIA

National Dementia Strategy Objective 7: Implementing the Carers’ Strategy for people with dementia

Family carers are the most important resource available for people with dementia. Active work is needed to ensure that the provision of the Carers’ Strategy is available for carers of people with dementia. Carers have a right to an assessment of their personal needs and can be supported through an agreed plan to support the important role they play in the care of person with dementia. This will include good-quality personalised breaks. Action should also be taken to strengthen support for children who are in caring roles, ensuring that their particular needs as children are protected.

Approximately two thirds of people living with dementia are cared for at home, the majority of that care being provided by family and friends. Supporting the family carer is crucial in enabling people with dementia to remain at home or in their choice of places to live. When assessing the client the care needs of the family carer must also be taken into account.

Suffolk Perspective

We were told:
“Carers should have easy access to their dementia support worker.”
Good, free, 24-hour, intermediate care to avoid long-term admission to residential care
“The strategy should focus on family/carer support as a prevention tool.”
“There are still rigid mindsets within statutory organisations on how the carers grant can be spent. This inhibits the assistance we can give to carers.”
“One 24-hour phone number (help!) to someone who knows the case/person.”

We will:
- Support and nurture family carers, ensuring equality and recognising they themselves may be physically frail or have disabilities. Build up peer support networks (such as Alzheimer Society Dementia Cafes/support groups).
- Listen to the family carer and instigate an early carers assessment.
- Develop a comprehensive range of support services to ensure that family carers are
  - Mentally and physically well; treated with dignity.
  - Not financially disadvantaged.
  - Recognised and supported as expert care partners.
  - Enjoying a life outside caring.
  - And that children are protected from inappropriate caring roles.
Safeguarding: We are aware that the Alzheimer's Society has recently published research highlighting that inadequate support mechanisms increase the risk of people with dementia being vulnerable to abuse from their Family Carers. As a consequence it is vital that family carers are clear how they can access information/advice and staff understand their roles and responsibilities in relation to safeguarding. In order to do so it is important that the following are in place:

- Training and education: family carers need to gain skills in the best way of caring for a person with dementia. For example, an understanding of the behavioural and psychological symptoms of dementia and how to cope is vital. This training must include making family carers “abuse aware”.
- Peer support networks: family carers want to know that they are not alone and to get practical advice from others who are in the same situation.
- Short breaks: It is vital that family carers have access to flexible and responsive short breaks, provided in a variety of settings.
- Psychological support: Family Carers for people with dementia can experience significant emotional distress including depression, stress and guilt.
- Information: having access to timely, pertinent information about rights and entitlements, the role of the Safeguarding Team and how to access it is crucial.

It is also acknowledged that Family Carers themselves are likely to be affected by abuse, and that this can add to the stresses and strains of fulfilling the Family Carer role.
LIVING WELL WITH DEMENTIA

National Dementia Strategy Objective 8:
Improved quality of care for people with dementia in general hospitals
Identifying leadership for dementia in general hospitals, defining the care pathway for dementia there, and the commissioning of specialist liaison older people’s mental health teams to work in general hospitals.

The National Audit Office has estimated the cost of dementia in general hospitals may be more than £6 million per average general hospital.

Some 70% of older people make up the acute inpatient occupation of hospital beds. Up to half of these may be people with a degree of cognitive impairment, including those with delirium and dementia. Hospitals are particularly challenging environments for people with memory and communication problems, with cluttered ward layouts, poor signage and other hazards. People with dementia in general hospitals have worse outcomes in terms of length of stay, mortality and institutionalisation. They are often viewed as ‘difficult to manage’ and require greater time to be given to them than resources often allow. In Suffolk there are examples of people with dementia whose average length of stay exceeds 21 days and in some cases this can be as much as 48 days see appendix 3.

Suffolk Perspective

We were told:
“Need all providers to work on dignity, understanding and awareness of people with dementia. We need a trained and consistent workforce who are supported and valued and can give the time needed to spend with individuals.”

“We need good prevention services to avoid admission plus access to free appropriate intermediate care to support the carer in a crisis.”

“[Should have] paid care workers used to the person to work with them in hospital alongside the general nurses.”

“The scope for improving the support and quality of care is very broad, with room for improvement in almost every area from diagnosis to end of life.”

“They did not know want or even to understand dad’s needs except for his broken leg!”

We will:
Empower the local dementia team to follow their patients admitted to hospital. They will to seek to gain discharge as early as possible working with hospital staff similar to the community matron long term condition models.
LIVING WELL WITH DEMENTIA

National Dementia Strategy Objective 9:
Improved intermediate care for people with dementia
Intermediate care which is accessible to people with dementia and which also meets their needs.

Intermediate care has twin objectives which are to avoid inappropriate hospital admissions/inappropriate bed occupancy and also the broader objective of enhancing peoples independence.

Intermediate care provides a link between different locations (home/hospital/residential care and vice versa) and between sectors (acute/primary/social care/housing) and between individual states (illness and recovery, or management of long term conditions). Its essence is that people are seen as a whole, not just in terms of cognitive and physical abilities but as individuals in a social setting.

Suffolk Perspective

We were told:
“[It is] important that Intermediate Care Services are able to focus on dementia as well as any physical needs.”
“There should be a seamless service in and out of hospital.”

We will:
• Promote independence and crisis prevention.
• Ensure access to the team is through a single point of access, usually a 24 hour telephone line.
• Develop more integrated services
• Use evidence-based methods to ensure access to rehabilitation includes psychosocial aspects.
• Train staff in dementia and access to advice and support from specialist mental health personnel.
• Look for innovative solutions that may avoid admission.
• Ensure Dementia Support Teams have access to the full range of intermediate care services available with their locality.
LIVING WELL WITH DEMENTIA

National Dementia Strategy Objective 10:
Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers

The needs of people with dementia and their carers should be included in the development of housing options, assistive technology and telecare. As evidence emerges, commissioners should consider the provision of options to prolong independent living and delay reliance on more intensive services.

Housing is central to the promotion and maintenance of independence. Housing should be based on need, not the environment in which it is provided so people with dementia should have a choice as to where they live, which will include a range of housing options, for example their own home supported by assistive/SMART technology and home care, extra care housing as well as residential care. Commissioners will need to work with partners, such as district and borough councils, housing associations and independent providers, to provide flexible housing options for people with dementia and their family carers.

In order to support people’s ability to remain living at home, a variety of mechanisms need to be adopted, both in support terms and “bricks and mortar” based. We will work together with Housing authorities (within both the current configuration of districts/boroughs, and within any subsequent unitary arrangements), Supporting People, housing associations and support provider agencies to ensure that these are in place.

Suffolk Perspective

We were told:
“One thing people don’t like is “change”; therefore for many moving is not a preferred option.”

“Support is needed to remain living at home – default position, assume no need for re-housing unless demonstrable positive reasons.”

“Are VSH services “doing what they are set up to achieve?”

“Work with building/planning – “Homes for Life” should include wiring for technology.”

We will:
• Make available Very Sheltered Housing (with and without Extra Care facilities).
• Offer supported housing options for younger people with dementia.
• Improve non-accommodation-based support funded by Supporting People.
• Ensure Home Improvement Agency (Care and Repair) services and Disabled Facilities Grants are available.
• Make appropriate aids and adaptations available for older people when needed so they can stay at home.
• Improve information to raise awareness of the full range of options.
• Develop 24-hour human response, Community alarms.
LIVING WELL WITH DEMENTIA

National Strategy Objective 11:
Living well with dementia in care homes
Improved quality of care for people with dementia in care homes by the development of explicit leadership for dementia within care homes, defining the care pathway there, the commissioning of specialist in-reach services from community mental health teams, and through inspection regimes.

Commissioners need to ensure that care homes provide a stimulating environment for people with dementia, with a range of activities.

Suffolk County Council is currently engaged in a review of residential services. Underpinning this is the concept that people want to retain their independence for as long as possible. The county council’s Care Quality Monitoring Team undertook a study in 2008 to identify reasons why people who are self-funding entered registered care homes. This identified a number of common factors that could influence the decision, including:

- Family carers’ own personal needs - including their own care needs, personal needs, work arrangements and proximity to their relative.
- Lack of information about alternatives.
- The suggestion or advice of a GP or health professional.
- Hospital discharge factors and pressures.
- Risk issues for someone living at home.
- Restrictions of care arrangements at home such as purchased care arrangements.

Suffolk Perspective

We were told:
“All care homes should have skills to support dementia.”

“Self-funders are often least well catered for and have a strong sense of “failure” – leading people to “get into care homes earlier than they should.”

“Care homes to work more closely with relatives.”

We will:
• Work with CSCI and other services to ensure care homes provide a stimulating environment for people with dementia, with a range of activities.
• Support staff in their training and development.
• Enable and encourage staff to interact and communicate with residents and foster an environment that encourages people with dementia to maintain their family relationships. Questions of cultural sensitivity are important here.
• Develop active partnerships with the independent sector to shape the service to increase the capacity and quality of provision for people with dementia and complex needs.
LIVING WELL WITH DEMENTIA

National Strategy Objective 12: Improved end of life care for people with dementia
People with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the Department of Health End of Life Care Strategy. Local work on the End of Life Care Strategy to consider dementia.

It is recognised that End of Life Care for people with dementia should respect the principles of supporting people (and their family carers) to exercise choice and control over where and how they die. It is envisaged that mainstream services should be able to offer these, but must respect the particular needs of people with dementia. This incorporates an awareness and understanding of how a person’s mind and behaviour changes as their dementia progresses. Services must ensure that they do not discriminate against people with dementia.

Suffolk Perspective

We were told:
“Support dignity wherever person is coming to end of life.”

“Planning for end stage – needs to be early solicitors costs a big issue – consideration to be given to procuring a dedicated service?”

Services to “…recognise cultural issues eg as people “regress to their mother tongue.”

Services to “…allow people to go when they are ready.”

We will:
• Ensure support services are in place.
• Put early end of life planning in place.
• Take account of the principles and tools of the Mental Capacity Act.
PART 3 - HOW ARE WE GOING TO ACHIEVE THIS?

RECOMMENDATIONS
In order to achieve the transformation envisaged by this strategy the following recommendations are made. In order to transform our commitments into reality this strategy will inevitably need to be a “living document”.

The National Strategy relies on the development of good practice as a precursor to further developments and investment decisions. We will be developing and reviewing an Implementation Plan and Performance Management dimensions on the basis of progress locally and developments nationally. In doing so we will adopt the following principles to inform the priority of the recommendations:

• Consultation feedback
• National Dementia Strategy Implementation Plan “early progress”.
• Must dos (eg “achieve joint-commissioning”).
• A need to manage the market rather than destabilise it.
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| 1. Raising Awareness and Understanding | 1. Improving public and professional awareness and the understanding of dementia | 1.1.1 An early high profile media campaign is undertaken as a priority across Suffolk as there is already raised public awareness following the launch of the National Dementia Strategy. A campaign of this nature must be a phased approach, developing and continuing over time as we can offer more information as the strategy implementation takes place.  
1.1.2 Accurate, accessible, evidence based information will be available to all people in Suffolk in a variety of formats and widely available. Information will meet the health and social needs of individuals and be culturally sensitive.  
1.1.3 Organisations will be encouraged to utilise their developed networks to broaden the distribution of information relating to dementia. Joint commissioning from the third sector should be expanded as a source of information on health and social care services. It should be the intention of the commissioners to seek partner organisations to develop and to distribute the type of information packs required to inform the general public, individuals with dementia and their families about dementia, diagnosis, help and support available. |
| 2. Early Diagnoses and Support | 2. Good-quality early diagnosis and intervention for all                   | 2.2.1 A written protocol to be written agreed and adopted for primary care services within Suffolk on the early diagnosis and referral pathways for people with symptoms which could be mild, moderate or severe dementia.  
2.2.2 Monitoring will take place to ensure GP practices routinely screens patients with known risk factors for dementia, such as coronary heart disease and stroke, during their annual review. |
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<tr>
<td>2. Early Diagnoses and Support</td>
<td>2. Good-quality early diagnosis and intervention for all</td>
<td>2.2.3 Routine screening can then be expanded, using a phased approach, to target the generic older people population (DH 2005). Screening can take place by professionals such as practice nurses trained in a core set of competencies. Routine screening is a brief process and involves asking some basic cognitive screening questions, which should be locally agreed between primary and secondary care. If a patient answers positively to either question then referral to a memory assessment service (MAS) is required. Using evidence based assessment tools, the initial memory assessment can be undertaken by specially trained primary care nurses (PNs, DN, HVs or MH link workers).</td>
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<td>2.2.4 The numbers of clients currently being seen in Suffolk in our memory clinics are 800, the models for this service delivery are variable and need to be better defined with given outcomes and standards. A target of 1600 would give an 80% detection rate based on current populations.</td>
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<td>2.2.5 The model of service recommended is a multidisciplinary (MDT), multiagency team. The National Dementia Strategy quotes 10.00 wte for a population of 50,000. This would suggest that we need to double this for Suffolk providing a skill mix of 20 wte staff. The team would use a defined core set of assessment tools which may be nationally devised. The MDT would consist of three tiers of worker:</td>
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<td>2.2.6 Dementia Support Worker-DSW a hybrid, generic, multi-skilled worker who closely links with the newly diagnosed person with dementia and their family and would act as the single point of contact for families. Initially, the DSW would be introduced at the time of diagnosis. They would have knowledge of health, social care, and third sector resources and be mature, skilled listeners, doers and able to use their own initiative, seeking help from the wider team as required. This would be a vital role and is very much the type of assistance that carers and people with dementia have been advocating. It is envisaged that they would be geographically located and attached to a given number of MAS’s and practices. Overtime the numbers of workers would need to be increased to enable 24 hour working as often crisis takes place at night and to cope with the demographic increase.</td>
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<tr>
<td>2. Early Diagnoses</td>
<td>2. Good-quality early diagnosis and intervention for all</td>
<td>2.2.7  Specialist dementia link nurse. These would provide the ‘conduit’ into ‘highly specialised’ secondary care services. They would provide a link within primary care, offer pre diagnosis support/counselling, post diagnosis counselling. They would undertake initial assessments in primary care, trigger social care assessment and provide care coordination during the diagnostic stages. They would also identify likely high intensity/vulnerable users of services and draw up long term care plans. They would work closely with the DCA to provide them with supervision, support and to ensure long term care plans are in place and reviewed. They would work to a defined catchment area.</td>
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<td>and Support</td>
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<td>2.2.8  Highly specialised secondary care workers. Medical consultants, clinical psychologists. These would provide diagnosis in equivocal cases, initiate treatment and provide support and supervision to the link nurses. They would provide clinic based assessments. It is possible this could be based in primary care settings i.e. room at GP practice and or in hospital dependent on what accommodation is available in given areas across Suffolk.</td>
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<td>2.2.9  Overall the model described will be looking at an early recognition and diagnosis service comprising 3.0 wte medical doctors, 8.0 wte nurses, 2.6 wte Occupational therapists, 2.0 wte psychologists, plus 7.0 wte support workers and 3.0 wte administration staff. This is consistent with recommendations in appendix 4 of the national strategy for a population of 100,000 over 65. The current memory clinic costs will need to be considered as part of this proposal. It has been suggested that if you then add social care input to this the process for the patient is much smoother and there is less points when the person call fall through traditional service pathways as they are supported from day 1.</td>
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<td>2.2.10 It is recommended that the long term aim be that Memory Assessments Services should operate an open access referral system.</td>
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<tr>
<td>2. Early Diagnoses and Support</td>
<td>3. Good-quality information for those with diagnosed dementia and their carers.</td>
<td>2.3.1 The new national document, along with an agreed set of local information should be given to all patients who attend the clinic and whose diagnosis is confirmed. The DSW, team members and all services delivering care for those with dementia should then have further agreed information packs available in different formats, which can be introduced as the disease progresses, is requested or as issues arise. All of the information should be held in common areas such as libraries, pharmacies, GP surgeries, vol. sector, clinics and hospitals etc.</td>
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<td>4. Enabling easy access to care, support and advice following diagnosis.</td>
<td>2.4.1 The role of the DSW be developed and training be commissioned to create the hybrid care worker who is key to supporting people with dementia and their family carers. The numbers of DSW’s initially to be defined as per the National Dementia Strategy. This number will need to be further increased as the numbers of people with dementia increase within the county.</td>
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<td>5. Development of structured peer support and learning networks.</td>
<td>2.5.1 Build on the current good practice already established in parts of Suffolk working with the third sector ensuring that there is a peer group set up in all major market towns which is well supported by transport systems, statutory services and meets the needs of the carer and cared for.</td>
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<td>3. Living Well with Dementia</td>
<td>6. Improved community personal support services.</td>
<td>3.6.1 Enhanced domiciliary care – Commissioners will assess the effectiveness of the pilot currently being undertaken in Waveney, and of services provided elsewhere in the country, to evaluate the capacity to support people living at home for longer, thereby avoiding the need to move towards more institutional forms of care. On this basis we will move towards equity of provision across the county.</td>
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<td>3.6.2 Home First – We will clarify the role of Home First with regard to people with dementia to ensure that the core objectives of the service are achieved, i.e. to provide short-term support, assessment and re-ablement to all new customers, recognising the need for continuity of care. This will ensure that people's needs are effectively identified and met at as early a stage as possible.</td>
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<td>3. Living Well with Dementia</td>
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<td><strong>3.6.3</strong> Short-break care - We will ensure that there is a range for service provision to provide Short-break care for people with dementia and their carers. This will include bed-based services within residential services, and also by ensuring the availability of day services that are intensive and skilled to provide a caring environment for people with dementia. The availability of day (and night) sitting services will be developed.</td>
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<td><strong>3.6.4</strong> Advocacy services - We will develop an advocacy strategy that takes account of the acknowledged shortfall in current provision, and also takes account of the enhanced awareness and rights arising from the Mental Capacity Act.</td>
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<td>7. Implementing the Carers’ Strategy for people with dementia.</td>
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<td><strong>3.7.1</strong> Family Carers Partnership Board – we will work with the Partnership Board to develop and implement the 10 priority outcomes identified in the Board’s Action Plan 2009-2013.</td>
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<td><strong>3.7.2</strong> Information packs - these will be available as a point of reference for Family carers as outlined in Recommendation 1.1.3 and 2.3.1 above.</td>
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<td><strong>3.7.3</strong> Day services to be available to: Provide intensive treatment that enables the person with dementia to return home in the evening; person-centred activities to maximise their skills; assessment of future needs and provide short break opportunities for carers.</td>
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<td><strong>3.7.4</strong> Short-breaks – A variety of services (including sitting services) should be commissioned to enable flexible ways of delivering respite care. We will work to ensure that there is equity of Short-break services available across the County. This will need to take account of the geography of the County, addressing both rural and transport issues, and in the context of the report on the “Future Direction of SCC Short Break (Respite) Services provided in Suffolk 2008&quot;.</td>
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<td>8. Improved quality of care for people with dementia in general hospitals.</td>
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<td><strong>3.8.1</strong> Identification of a senior clinician within the general hospital to take the lead for quality improvement in dementia in the hospital.</td>
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<td><strong>3.8.2</strong> Development of an explicit care pathway for the management and care of people with dementia in hospital, led by that senior clinician.</td>
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<td>3. Living Well with Dementia</td>
<td>8. Improved quality of care for people with dementia in general hospitals.</td>
<td>3.8.3 The care of the person with dementia such as life diaries which give a more in depth understanding of the persons norms and inclusion of main carers input to the assessment process.</td>
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<td>3.8.4 The gathering and synthesis of existing data on the nature and impacts of specialist liaison older people’s mental health teams working in general hospitals.</td>
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<td>3.8.5 Implementation of nutrition action plans for this client group as high priority</td>
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<td>3.8.6 Removal of the stigma of diagnosis of dementia by awareness training and through working with care providers able to cope with the needs of this patient group</td>
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<td>3.8.7 Commissioning of specialist liaison older people’s mental health teams to work in general hospitals</td>
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<td>3.8.8 Training of general staff in order to better understand and manage these patients</td>
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<td>9. Improved intermediate care</td>
<td>9. Improved intermediate care for people with dementia</td>
<td>3.9.1 Provide an expert multiagency, multi-professional health and social care service to both service users, those who care for them, and supporting teams such as those commissioned in the third sector or from housing. This service will be in accordance with evidence based practice and NICE guidelines, and include the prescribing of required medications, from diagnosis until death</td>
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<td>for people with dementia</td>
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<td>3.9.2 Provide information and post diagnostic counselling to people with dementia and their carers, that is co-ordinated with commissioned information services</td>
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<td>3.9.3 Work in partnership with general health and social care colleagues to plan care that promotes independence and avoids unnecessary admission, particularly in relation to the management of other long term conditions, for example, CHD and Diabetes</td>
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<td>3.9.4 Provide an in-reach liaison service to assist, both through training and faceto-face work, in the early identification, diagnosis and management of mental health conditions within Acute Trusts.</td>
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<td>3. Living Well with Dementia</td>
<td>9. Improved intermediate care for people with dementia</td>
<td>3.9.5 Intermediate Care teams and the liaison service will assist in early discharge planning and prevention of delayed discharges.</td>
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<td>3.9.6 Work in partnership with the Crisis Resolution Home Treatment (CRHT) service.</td>
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<td>3.9.7 Co-ordinate services, and work closely with the independent sector and voluntary organisations</td>
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<td>3.9.8 Liaise and refer people with dementia to specialist support services as and when required, for example, Independent Mental Capacity Advocate’s (IMCA’s), Deprivation of Liberty Safeguard specialists, specialists in the needs of younger people with dementia and people with learning disabilities, and dementia, drug and alcohol misuse.</td>
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<td>3.9.9 To contribute to assessments for continuing health care by providing accurate and timely information on individuals needs</td>
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<td>3.9.10 To contribute to other multi-disciplinary assessments by providing accurate and timely information on an individuals needs, including the needs of carers.</td>
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<td>10. Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers.</td>
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<td>3.10.1 Assistive technology – at a time when the market for technology is rapidly expanding, it is crucial to ensure that people know what is available, and how to access this. As a result, we will work with the Suffolk Assistive Technology Project Board to ensure that Assistive Technology and Community Alarm services are available for those with Dementia and their Family Carers to support their capacity and capability to remain living at home.</td>
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<td>3.10.2 Adaptations – we will ensure a co-ordinated approach to supporting people to get the adaptations and equipment need to support their ability to remain living at home. This will entail working together with Supporting People, District/Borough Councils, Housing associations, Care and Repair Agencies and Equipment services to ensure that these are available and forthcoming.</td>
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<td>3. Living Well with Dementia</td>
<td>10. Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers.</td>
<td>3.10.3 Very Sheltered Housing – we will ensure that Very Sheltered housing (including Extra Care) options are more widely available, by developing new services, incorporating rented and leasehold options. We will also review services to ensure that they are providing what they are “doing what they are set up to achieve”</td>
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<td>11. Living well with dementia in care homes</td>
<td>3.11.1 We will strengthen the quality and robustness of management information, focussing on Outcomes held by ACS in order to raise expectations, identify areas for action and ensure that the National Dementia Strategy recommendations are adopted. We will also develop systematic contract management arrangements in place to monitor the quality and performance of either in-house or external care homes. This will combine with input from individual assessment issues to raise the levels and quality of care.</td>
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<td>3.11.2 “Not so many, so soon” – we will work to ensure that self-funders moving into residential care, do so on a basis of need rather than other factors that could be addressed (highlighted by the Care Quality Monitoring Survey)</td>
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<td>3.11.3 We will seek to influence the development of new services to ensure the availability of services across the County.</td>
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<td>12. Improved end of life care for people with dementia</td>
<td>3.12.1 Ensure the Suffolk Joint Palliative Care Strategy takes account of the specific needs of people with dementia.</td>
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WORKFORCE DEVELOPMENT

In order to achieve these recommendations and the associated transformation of the experiences of people with dementia and their family carers in Suffolk it is clearly crucial that all staff working with them have both the necessary knowledge and skills to enable them to provide the services needed. With this in mind, this Strategy recognises the importance of improving the standards of knowledge and awareness of dementia amongst health and social care professionals was first reflected in the ‘Dementia UK’ report (Alzheimer’s Society 2007) and in the National Audit Office report (NAO 2007) and has been a consistent theme throughout the listening and consultation events for the National Dementia Strategy. People with dementia and their family carers have asserted that this is imperative if the quality of care and service given is to improve.

This need to improve standards is being driven forward in the Strategic Health Authority’s (SHA) vision ‘Towards the Best Together’ (2008), the NHS next stage review (2008) and the National Dementia Strategy (2009).

Objective 13 of the National Dementia Strategy is:

‘An informed and effective workforce for people with dementia’

with the outcome:

‘All health and social care staff involved in the care of people with dementia to have the skills needed to provide the best quality care in the roles and in the settings where they work. To be achieved through effective basic training, and continuous professional and vocational development in dementia’.

Investment in dementia training and education programmes will not only improve the quality of care for people with dementia and their family carers, it can also improve morale amongst the workforce and help to address some of the recruitment and retention challenges faced by employers.

This strategy aims to promote an integrated model of training and education for all staff from all sectors, including medical staff, the benefits of which are:

• People and their family carers will be supported and cared for by a fully trained integrated workforce
• There will be standardised and improved level of knowledge across organisations
• Consistency in the quality of care across the county
• Cost effectiveness as less duplication and opportunity to pool resources
• Specialised knowledge will improve quality of information given to the public and people living with dementia and their carer/s
• Specialist knowledge of unpaid carer/s
• Promoting independence and avoid admission to hospital
• Networks can be developed for ongoing support
• Input to staff can be coordinated with input to managers to support staff training

Transforming the quality and experience of dementia care for the people of Suffolk
PRINCIPLES OF COMMISSIONING DEMENTIA TRAINING AND EDUCATION

NHS Suffolk, NHS Great Yarmouth and Waveney and Suffolk County Council and partner organisations will apply the following principles to commissioning dementia training and education:

- A whole systems integrated approach based on a clinical, biophysical and social outcomes for people living with dementia and their family carers.
- Training and education needs to have a clear practical focus relevant to the work of the learners – where possible addressing real needs of real clients This will entail the development of differential levels of learning.
- Training and education should be commissioned to support continued and sustained learning, rather than ‘ad hoc’ programmes that have little sustainable impact on quality of care.
- Training and education should be progressive and mapped to a skills escalator, for example, the NHS skills escalator.
- Training and education programmes should be accredited, or externally verified, and linked to vocational awards wherever possible, for example, National Vocational Qualifications (NVQs).
- Training and education programmes should include a range of teaching methodologies that can adapt to individual learning styles, including long distance learning.
- Commissioned training and education programmes should be made available to family carers.
- Training and education is evidence based and contemporaneous and should meet regulatory standards.
- Mandatory specialist vocational courses on dementia should be commissioned for all care staff who work directly with people with dementia.
- Mandatory training and education around dementia, raising awareness, skills, attitudes and dignity should be an integral part of foundation training and education of all health, social care and third sector staff and commissioners should work with foundation training and education organisations to ensure this is implemented.
- A workforce must be available with the skills to manage younger people with dementia and people with learning disabilities and dementia and training and education should be available that targets the needs of these specific groups of people.
- Equality- training and education should be sensitive to the needs of people from different cultural and ethnic backgrounds.
- The approach to training and education takes account of existing and developing ethical frameworks, to facilitate and assist the management of dilemmas occurring when making decisions about dementia care.
- Commissioners will expect all training and education providers to demonstrate how all training and education programmes promote the dignity and respect of the individual.
- Training and education at a team level is preferable for sustained quality improvements.
• Training and education providers need to ensure organisational managers understand the reasons for training and education and commit to supporting staff through the training and education process and subsequent change in practice.
• Commissioned training and education programmes must be independently evaluated for impact on quality of care for people with dementia and their family carers.
• Training and education should influence regulatory standards.

Feedback from consultation

• Practitioners need much more awareness of what dementia really means.
• People need education to know what to look for.
• GP's really don't understand the problems and delay referring for diagnosis.
• Domiciliary care staff are not able to meet dads needs – some of its time but a lot of it is about understanding the illness.
• Staff need to understand the principles of what dignity means to people with dementia.

Suffolk Perspective

The mapping exercise demonstrated a limited number and level of training being delivered within the county, the vast majority of courses are levelled at the basic support worker and there is little evidence of courses on offer for professional staff. Suffolk commissioners are keen to make dementia everyone's business and therefore would want to incorporate dementia modules into all general training programmes from care assistants through to medical training.

This means that all staff who may have direct contact with people with dementia and their family carers will have received dementia training and education to develop the knowledge and skills to effectively respond to their needs. Training will support the concepts of Personalisation, and also ensure that staff are aware of how to Safeguard Vulnerable Adults with dementia. This will include staff working within the health, social care and housing sectors, whether within the statutory sectors or the 3rd (voluntary or private) sectors.

Whilst we may not directly commission training for professionals such as police, fire brigade, bank staff; or for staff within services such as transport, utility companies, major supermarkets etc we would want to heavily influence training establishments to offer awareness training on the subject of dementia as much of the experience of the person with dementia is that there is a real lack of understanding of their needs.

i) Skills and Experience of Trainers

Commissioners will ensure local training and education providers have the necessary knowledge and skills to provide training and education on dementia. Trainers/Educators should be able to provide evidence of their experience of working with people with dementia and their family carers and will need to demonstrate specific knowledge of different care environments. Trainers/Educators should have, or be prepared to work towards, an accredited training/education qualification, for example, the Alzheimer’s Society Approved Trainers Scheme.
Trainers/Educators will evidence commitment to ongoing professional development. Trainers/Educators and training and education programmes will need to be externally evaluated on an annual basis. This could be achieved through external peer review and through a learner’s evaluation report that is externally prepared, or internally prepared and externally verified. The learner’s evaluation report will be interviews with a random sample of learners.

ii) Training methodologies
Commissioners will ensure that training and education providers can evidence that a range of teaching methods are available, and accessible, to learners to meet individual learning styles. An integrated training and education approach will provide opportunities for people to learn in their own teams, separate groups or as individuals and be available in a variety of locations, including a learner’s own home via distance and internet learning programmes (the latter is intended as an option for family carers).

iii) Learning outcomes
Skills for Care (www.skillsforcare.org.uk) have produced a knowledge set for dementia, with learning outcomes, that has been developed in conjunction with Skills for Health (http://www.skillsforcare.org.uk/developing_skills/knowledge_sets/dementia.aspx).

Commissioners should broadly base their expectations of training and education providers to achieve these learning outcomes with the following additions:

- Training and education should promote independence through the personalisation programme, individual budgets, direct payments, assistive technology, housing, leisure and intermediate care.
- Training and education should highlight the specific needs at specific stages of dementia, for example the early, middle and later stages of dementia.
- Training and education should include the understanding of perplexing behaviours and the management of the environment, particularly in relation to visual and spatial awareness.
- Training and education should focus on prevention of crisis.
- Training and education should focus on enabling people with dementia and their family carers to choose how they would like to be cared for at the end of life.
- Training and education should promote the individuality of a person with dementia by enabling learners to understand how to apply life stories and dementia care mapping.
- Training and education should enable learners to support people in the early stages of dementia, for example, post diagnostic counselling.
- Training and dementia should have a focus on the specific needs of younger people with dementia, people with alcohol related dementia and people with a learning disability and dementia.
- Training and education will provide a wide range of ethical frameworks to support decision making.
- Understanding of risks and that taking risks can be integral to quality of life It is the role of commissioners to ensure that the overall outcome of any training and education programme will be to equip learners with the necessary practical skills and
knowledge that has a proven impact on the quality of services provided to people with
dementia and their family carers. Simply ensuring that learning outcomes are met is not
enough to demonstrate improvements in quality of care, so commissioners must ensure
that training and education providers have the means to assess the practical impact of
the training and education provided. This may be achieved in a number of ways:

- Dementia care mapping, QUIS, SOFI
- Learner self assessment and organisational assessments of learners practice
- Learning log diaries with evidence of improvements in practice
- Assessment of practical competencies by training and education organisation
- Peer review
- Feedback from people with dementia and their family carers

iv) Organisational responsibility

Organisations, including residential care, that are commissioned to provide care for
people with dementia have a responsibility to ensure that they have a trained, educated
and skilled workforce that can meet the needs of people with dementia and their family
carers, in accordance with the National Dementia Strategy. Commissioners will ensure
that organisations have an appropriately trained, educated and skilled workforce, in
accordance with the principles of this document.

This means that all staff who may have direct contact with people with dementia and
their family carers will have received dementia training and education to develop the
knowledge and skills to effectively respond to their needs. This will include staff working
within the health, social care and housing sectors, whether within the statutory sectors or
the 3rd (voluntary or private) sectors.

Each organisation should promote the use of dementia champions to provide leadership
and ongoing support to people who have undertaken training and education and to
ensure that change in practice is ongoing and sustained. A dementia champion does not
have to be a senior manager – anyone should be able to take on this role.

Cost considerations:

Commissioners should recognise the importance of third sector services and ensure that
voluntary service providers achieve full cost recovery for the services provided

References:

• Alzheimer’s Society (2007) Dementia UK.
• East of England SHA (2008) Towards the best together. EML
• Hayes, K (2007) Devising the poetry of dementia pp 28 Journal of Dementia Care
  London
• National Audit Office (2007) Helping People through mental health crisis:The role of
  crisis resolution and home treatment services. HMSO
PART 4 - HOW ARE WE GOING TO KNOW WE ARE SUCCESSFUL?

QUALITY INDICATORS

It is recognised that there is a need to develop systems of recording, management and reporting of Quality Indicators. Also, that there is scope to develop, in accordance with World Class Commissioning, incremental “stretch targets” within a Quality Information Framework as elements of the Strategy dovetail, and build up. With this in mind, Suffolk’s Dementia Board will review and develop these Indicators on an annual basis. We will also look the outcomes of pilot services to further develop and enhance these.

Section 1 – Raised Awareness and Understanding of Dementia

Quality Indicators:

In addition to existing quality indicators providers should record annually:

• User and family carer survey on satisfaction with the source, access, accuracy, timeliness and quality of the information provided, to include point of referral.

• % of clinics, day centres, care homes, libraries, NHS Trusts, Local authority offices, GP practices and online resources providing access to specialist information on dementia and uptake of that information.

• Numbers attending dementia support services within the voluntary sector and numbers of new attendee’s.

• Numbers of people referred for information prescriptions (recorded by referrer).

• Numbers of people presenting with information prescriptions and numbers of visits required to get the information needed.

Section 2 - Early Diagnoses and Support

Quality Indicators:

• READ coding for recording screening at CHD annual review, and outcome of screening, should be agreed and implemented by April 2010.

• All PCTs to work with their GP practices to have a dementia protocol in place by April 2010.

• Time of referral to specialist treatment should initially not be longer than 18 weeks, which includes time to assess and confirm diagnosis. This is in accordance with the National Standards on access.

• Date of referral to memory assessment service and date seen to be recorded.

• Date of referral from memory assessment service to date seen by specialist (where indicated) to be recorded.

• Rates of detection in primary care monitored from April 2010 (targets for %age of expected cases identified).

• Record number of people referred (by GPs) to memory assessment services that have had a medical review, urinalysis and routine blood investigations. Commissioners should aim to achieve a 100% of all referrals by October 2009.

• Providers to record the source of referrals to memory assessment services.

• Numbers and throughput to MAS recorded.

• Questionnaire on persons experience.

• Numbers of families supported by DSW.
• Distribution and availability of DSW’s.
• Good quality of information is available at time of diagnosis and received by all patients confirmed as having dementia.
• Equitable access to information for all, taking Equality issues into account.

SECTION 3 Living Well with Dementia

Quality Indicators:
• Record date of first appointment with integrated team. Time of referral to specialist treatment should not be longer than 18 weeks, which includes time to assess and confirm diagnosis. This is in accordance with the National Standards on access.
• Record % of people seen who have a follow up appointment arranged.
• Record levels of prescribing of cholinesterase inhibitors by April 2009.
• Record the numbers of people with dementia who have access to telecare and tele-health by April 2009.
• Record the number of people with dementia who are offered and uptake, individual budgets.
• Record the number of people with dementia who are referred, and subsequently access intermediate care services by April 2009. All people with dementia should have immediate access to intermediate care, if indicated, within the current intermediate care performance specifications.
• Record numbers of admissions, and repeat admissions, to any hospital for dementia related illness.
• Lengths of stay in acute trusts for people with dementia should reduce to be in line with people without dementia, for the same condition, by April 2011.
• The liaison service should record the number of people referred and seen by the service (expect 95% of all referrals to be seen by the service and have a coordinated discharge plan, to include onward referral rates).
• Record the number of Delayed Transfers Of Care (DTOC’s) for people with dementia (expect this number to fall significantly with a fully integrated service).
• Annual service user and family carer satisfaction survey on the accessibility, responsiveness and quality of service provided. Surveys should be conducted independently of the service provider and an annual report submitted to the commissioning organisation detailing an action plan for service improvement.
• Annual report to commissioning organisations of the numbers of complaints and Serious Untoward Incidents (SUI’s) received, detailing an action plan for service improvement.
• Providers to record the number of staff on each in-patient ward who have received training on dementia. Evidence of all dates and course attended to be provided upon request.
• Lengths of stay in acute trusts for people with dementia should reduce to be in line with people without dementia, for the same condition, by April 2011.
• Record numbers of people using day services.
• Record numbers of new referrals to day services.
• Record numbers of people accessing day services during crisis.
• Record the number of family carers offered and accessing, short breaks from April 2009.
• Record the number of family carers offered and accessing, direct payments from April 2009.
• CSCI record improvements in the standards of care provided by home care services over a five year period.
• Annual family carer satisfaction survey on the accessibility, responsiveness and quality of service provided. Surveys should be conducted independently of the service provider and an annual report submitted to the commissioning organisation detailing an action plan for service improvement.
• Annual service user and family carer satisfaction survey on the accessibility, responsiveness and quality of service provided. Surveys should be conducted independently of the service provider and an annual report submitted to the commissioning organisation detailing an action plan for service improvement.
• Annual report to commissioning organisations of the numbers of complaints and SUIs received, detailing an action plan for service improvement.
• By March 2010, CRHT to be available to anyone over the age of 18 years.
• Reduction in overall bed occupancy and lengths of stay for older people following the commencement of CRHT, in accordance with DH expectations.

Achieving this reduction can be measured by comparing the numbers of admissions, and lengths of stay, in the two years prior to the CRHT commencing with the present year.
• CRHT team to record the numbers of admissions that had been notified to, and seen by, the CRHT service prior to admission.
• Annual service user and family carer satisfaction survey on the accessibility, responsiveness and quality of service provided. Surveys should be conducted independently of the service provider and an annual report submitted to the commissioning organisation detailing an action plan for service improvement.
• Annual report to commissioning organisations of the numbers of complaints and SUIs received, detailing an action plan for service improvement.
• A reduction in the number of people going in to long term residential care over a five year period.
• Record the number of people who are offered, and access, assistive technology and extra care housing.
• An increase in the number accessing day care services.
• Record the number of people with dementia who are offered, and uptake, with individual budgets.
• CSCI record improvements in the standards of care within care homes over a five year period.

WORKFORCE DEVELOPMENT

Skills and Experience of Trainers

Quality Indicators:
• 100% of commissioned training and education organisations to provide evidence of all trainers/educators qualifications and experience/references in an annual report to commissioners by April 2010.
• 100% of all trainers/educators to have, or be working towards, an accredited training/education qualification by April 2010. Evidence of this to be supplied to commissioners in the annual report.
• Annual report on the accessibility, responsiveness and quality of training and education provided, which is submitted to the commissioners detailing an action plan for service improvement by April 2010.

• Commissioners to keep a register of trainers/educators by April 2010.

Training Methodologies
Quality Indicators:
• Annual report on the accessibility, appropriateness, variety and quality of the teaching methods offered to learners, which is submitted to the commissioners detailing an action plan for service improvements by April 2010.

• Record the numbers of in-house trainers/educators within each organisation by April 2010.

Learning outcomes
Quality Indicators:
• 100% of commissioned training and education organisations to provide evidence that curriculum’s meet the required learning outcomes by April 2010.

• 100% of commissioned training and education organisations to provide evidence, in the annual report to commissioners, that training and education is having a practical impact on the quality of care provided.

• 90% of all foundation courses to include training and education on dementia and dignity by Sept 2010.

• Annual service user and carer satisfaction survey on the accessibility, responsiveness and quality of service provided. Surveys should be conducted independently of the service provider and an annual report submitted to the commissioning organisation detailing an action plan for service improvement.

This is the responsibility of the care provider, not the training and education provider, as detailed in the overall integrated commissioning strategy for dementia.

• By April 2011, a reduction in the use of PRN medication to control behaviour as the workforce become more skilled in managing challenging behaviour.

* Improved training and education will enable organisations to achieve the other quality indicators that are detailed in the overall integrated commissioning strategy for dementia.

Organisational responsibility
Quality Indicators:
• All staff who may have direct contact with people with dementia and their family carers to have received dementia training and education within 5 years. This will include staff working within.

• Providers to record the number of staff employed in each service who have received training and education on dementia. Evidence of dates and course attended to be provided upon request.

• Organisations to record the number of dementia champions within the organisation and report to commissioners in the annual report (aim for each care environment to have at least one dementia champion by April 2010).
This Strategy has been developed to address the growing need to have a cohesive response to the needs of people with dementia and their family carers in Suffolk. This is to ensure that we are truly able to transform the quality and experience of services for people with dementia. The escalating demographics mean that to “do nothing” is not an option, and in the process we will ensure that services:

- Are Person-centered with an inclusive Care Pathway that works to educate, reduce stigma and actively support those affected by dementia.
- Are Jointly developed and commissioned with joint management systems introduced to ensure that there is a forward-looking service that delivers quality and value for money.
- Reduce inequity of provision and best supports those who are marginalized.
- Recognise that the needs of Family Carers are as important as the Cared for.

Mr A is an 84 year old former school teacher living with his wife. She has arthritis and they both have begun to worry about his forgetfulness.

Transforming the quality and experience of dementia care for the people of Suffolk
Transforming the quality and experience of dementia care for the people of Suffolk
Appendix 1

Demographic detail

<table>
<thead>
<tr>
<th>County</th>
<th>Year 2008</th>
<th>Year 2015</th>
<th>Year 2025</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bedfordshire</td>
<td>4,115</td>
<td>5,010</td>
<td>7,072</td>
</tr>
<tr>
<td>Cambridgeshire</td>
<td>6,604</td>
<td>8,146</td>
<td>11,615</td>
</tr>
<tr>
<td>Essex</td>
<td>17,311</td>
<td>20,602</td>
<td>27,829</td>
</tr>
<tr>
<td>Hertfordshire</td>
<td>12,054</td>
<td>13,998</td>
<td>18,059</td>
</tr>
<tr>
<td>Norfolk</td>
<td>12,714</td>
<td>15,072</td>
<td>20,621</td>
</tr>
<tr>
<td>Suffolk</td>
<td>9,870</td>
<td>11,733</td>
<td>16,327</td>
</tr>
</tbody>
</table>

Table 1 – Figures are for total population aged 65 years and above (Projecting Older People Population Information System 2008).

<table>
<thead>
<tr>
<th>Suffolk</th>
<th>Year 2008</th>
<th>Year 2015</th>
<th>Year 2025</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total population aged 30-64 predicted to have early onset dementia</td>
<td>199</td>
<td>204</td>
<td>232</td>
</tr>
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</table>

Table 2 – Figures are for total population aged 30-64 years (Projecting Older People Population Information System 2008)

England Prevalence of Dementia 65+

Transforming the quality and experience of dementia care for the people of Suffolk
Transforming the quality and experience of dementia care for the people of Suffolk

### Prevalence of Dementia 65+ Suffolk County and Suffolk PCT

<table>
<thead>
<tr>
<th>Year</th>
<th>Suffolk County</th>
<th>Suffolk PCT</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008</td>
<td>9,842</td>
<td>7,875</td>
</tr>
<tr>
<td>2010</td>
<td>10,210</td>
<td>8,186</td>
</tr>
<tr>
<td>2015</td>
<td>11,745</td>
<td>9,443</td>
</tr>
<tr>
<td>2020</td>
<td>13,696</td>
<td>10,993</td>
</tr>
<tr>
<td>2025</td>
<td>16,352</td>
<td>13,147</td>
</tr>
</tbody>
</table>

### Prevalence of Dementia 65+ Per District

<table>
<thead>
<tr>
<th>District</th>
<th>2008</th>
<th>2010</th>
<th>2015</th>
<th>2020</th>
<th>2025</th>
</tr>
</thead>
<tbody>
<tr>
<td>Babergh DC</td>
<td>1,291</td>
<td>1,332</td>
<td>1,569</td>
<td>1,825</td>
<td>2,190</td>
</tr>
<tr>
<td>Forest Heath</td>
<td>646</td>
<td>654</td>
<td>763</td>
<td>893</td>
<td>1,076</td>
</tr>
<tr>
<td>Ipswich</td>
<td>1,456</td>
<td>1,494</td>
<td>1,586</td>
<td>1,752</td>
<td>1,982</td>
</tr>
<tr>
<td>Mid Suffolk</td>
<td>1,213</td>
<td>1,271</td>
<td>1,504</td>
<td>1,764</td>
<td>2,115</td>
</tr>
<tr>
<td>St Edmundsbury</td>
<td>1,314</td>
<td>1,371</td>
<td>1,610</td>
<td>1,919</td>
<td>2,343</td>
</tr>
<tr>
<td>Suffolk Coastal</td>
<td>1,955</td>
<td>2,064</td>
<td>2,411</td>
<td>2,840</td>
<td>3,441</td>
</tr>
<tr>
<td>Waveney</td>
<td>1,967</td>
<td>2,024</td>
<td>2,302</td>
<td>2,703</td>
<td>3,205</td>
</tr>
<tr>
<td>Suffolk County</td>
<td>9,842</td>
<td>10,210</td>
<td>11,745</td>
<td>13,696</td>
<td>16,352</td>
</tr>
</tbody>
</table>

Transforming the quality and experience of dementia care for the people of Suffolk
Appendix 2

Key influencing documents

• National Dementia Strategy (2009).
• NHS next stage review (2008).
• Putting People First (2008).
• Towards the best together (2008).
• Valuing People Now (2007).
• Carer’s Strategy (2008).
• End of Life Strategy (2008).
• See me, not just the dementia –CSCI (2008).
• NICE guidelines and technical appraisals (2006).
• National Service Frameworks on Mental Health, Older People, Coronary Heart Disease and Long Term Conditions, particularly in relation to healthy living.
• Our Health, Our Care, Our Say (DH 2006).
• The Commissioning Framework for Health and Wellbeing (DH 2006).
• The World Class Commissioning Framework (DH 2007).
• The NHS Operating Framework (DH 2008).
• Mental Capacity Act 2005: deprivation of liberty safeguards.
• Everybody’s Business –Integrated mental health services for older adults: a service development guide (CSIP 2005).
• Suffolk County Council’s Adult and Community Services commissioning strategy.
• Suffolk County Council Corporate Priorities.
• NHS Suffolk Strategic Plan.
• Healthy Ambitions Strategy.
• Suffolk County Council’s Adult and Community Services Plan 2008-11.
<table>
<thead>
<tr>
<th>Service Area</th>
<th>Name of Service</th>
<th>Provider</th>
<th>Detail</th>
<th>Geographical Area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information and Advice</td>
<td>All</td>
<td>Info link</td>
<td>Web-based</td>
<td>Countywide</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SCC</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Information on Prescription Project</td>
<td>SCC</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mental Capacity Act - Professional</td>
<td>SCC</td>
<td>Raising awareness re MCA, developing policies and processes, and</td>
<td>Great Yarmouth and Waveney are covered by the two separate branches Countywide into 3 localities East, West and North</td>
</tr>
<tr>
<td></td>
<td>Advisor</td>
<td></td>
<td>providing guidance and advice</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Alzheimer's Society</td>
<td>Vol Sec</td>
<td>Great Yarmouth Branch. Lowestoft &amp; Waveney Branch. (Both branches</td>
<td>Great Yarmouth and Waveney are covered by the two separate branches Countywide into 3 localities East, West and North</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>provide this service)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>YPWD services</td>
<td>Age Concern</td>
<td>Talkabout Suffolk, web site, leaflets</td>
<td>Countywide</td>
</tr>
<tr>
<td></td>
<td>Museum Loan boxes</td>
<td>Museums and</td>
<td>Reminiscence equipment</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Alzheimer's</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Community Mental Health Teams</td>
<td>NWMMH</td>
<td>Teams based in Great Yarmouth and Lowestoft. Not dementia specific</td>
<td>Great Yarmouth and Waveney PC area</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Foundations</td>
<td></td>
<td></td>
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<td></td>
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<td>NHS Trust</td>
<td></td>
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<tr>
<td>Available training on dementia</td>
<td>All</td>
<td>Kerrison</td>
<td>Professional social care staff (not ongoing currently)</td>
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<tr>
<td></td>
<td>Reminiscence techniques</td>
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<td></td>
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<tr>
<td></td>
<td>Very few specific courses available</td>
<td>Lowestoft</td>
<td>6 week Dementia Course</td>
<td>Waveney</td>
</tr>
<tr>
<td></td>
<td></td>
<td>College</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Changing culture in Dementia</td>
<td>Kerrison</td>
<td>Social Workers - Managers and team leader level</td>
<td>3 days available quarterly</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Supporting people with dementia</td>
<td>Kerrison</td>
<td>Care workers in residential and VSH schemes</td>
<td>1 day course Monthly in localities</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Living at home with dementia</td>
<td>Kerrison</td>
<td>For home 1st and other Dom care staff in stat/vol/private sector</td>
<td>1 day course Monthly in localities</td>
</tr>
<tr>
<td>Service Area</td>
<td>Name of Service</td>
<td>Provider</td>
<td>Detail</td>
<td>Geographical Area</td>
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<td>Diagnostics</td>
<td>Younger people with dementia</td>
<td>Kerrison</td>
<td>Bespoke training for individual services</td>
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<td></td>
<td>Dementia Mapping</td>
<td>SCC</td>
<td>Voluntary Sector</td>
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<td>Mental Capacity Act- raising awareness re MCA policy development guidance &amp; support to all professionals</td>
<td>SCC</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>OLDER PEOPLES MENTAL HEALTH SERVICES</td>
<td>NWMH Foundations NHS Trust</td>
<td>Training on a formal and informal basis is available from all of these professionals and voluntary sector and to the identified professional groups</td>
<td></td>
</tr>
</tbody>
</table>
|              | Waveney Alzheimers Treatment Service | NWMH Foundations NHS Trust | Diagnostic and treatment available but not in a formal clinic set up. Most services delivered in service users' own homes. After 9 months discharged back to Primary Care is treatment progressing well. | Lowestoft and Waveney area  
<p>|              | Great Yarmouth Memory Clinic | NWMH Foundations NHS Trust | Diagnosis and treatment available both in a formal clinic and within the clients own home or residential care setting. 3 formal clinics run weekly. DV's available on request of G.P. | Great Yarmouth Area |</p>
<table>
<thead>
<tr>
<th>Service Area</th>
<th>Name of Service</th>
<th>Provider</th>
<th>Detail</th>
<th>Geographical Area</th>
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<tr>
<td></td>
<td>Memory Clinics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Outpatients</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>August 07 - July 08</td>
<td></td>
<td></td>
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<table>
<thead>
<tr>
<th>Provider</th>
<th>Schedule Desc</th>
<th>First Activity Count</th>
<th>F/U Activity Count</th>
<th>Total Activity Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>SUFFOLK MENTAL HEALTH PARTNERSHIP NHS TRUST</td>
<td>700: Learning Disabilities</td>
<td>86</td>
<td>516</td>
<td>602</td>
</tr>
<tr>
<td></td>
<td>710: Mental Illness</td>
<td>1,914</td>
<td>2,848</td>
<td>4,898</td>
</tr>
<tr>
<td></td>
<td>715: Old Age Psychiatry</td>
<td>674</td>
<td>1,494</td>
<td>2,168</td>
</tr>
<tr>
<td>Total</td>
<td>2,674</td>
<td>4,994</td>
<td>7,668</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Provider</th>
<th>Schedule Desc</th>
<th>First Activity Count</th>
<th>F/U Activity Count</th>
<th>Total Activity Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>IHT</td>
<td>400: Neurology</td>
<td>2,079</td>
<td>2,912</td>
<td>4,991</td>
</tr>
<tr>
<td></td>
<td>410: Geriatric Medicine</td>
<td>1,213</td>
<td>1,411</td>
<td>2,624</td>
</tr>
<tr>
<td>Total</td>
<td>3,292</td>
<td>4,323</td>
<td>7,615</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Provider</th>
<th>Schedule Desc</th>
<th>First Activity Count</th>
<th>F/U Activity Count</th>
<th>Total Activity Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>WSH</td>
<td>400: Neurology</td>
<td>1,218</td>
<td>1,268</td>
<td>2,486</td>
</tr>
<tr>
<td></td>
<td>410: Geriatric Medicine</td>
<td>247</td>
<td>383</td>
<td>630</td>
</tr>
<tr>
<td>Total</td>
<td>1,465</td>
<td>1,651</td>
<td>3,116</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>4,757</td>
<td>5,974</td>
<td>10,731</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Provider</th>
<th>Name of Service</th>
<th>Geographical Area</th>
</tr>
</thead>
<tbody>
<tr>
<td>MATS</td>
<td>Memory Assessment Service</td>
<td>West</td>
</tr>
<tr>
<td>Memory Clinic</td>
<td>Memory Assessment Service</td>
<td>East</td>
</tr>
<tr>
<td>SOCs</td>
<td>Most monitoring of AcHEI’s is done in the Nurse led SOC clinics</td>
<td>West</td>
</tr>
<tr>
<td>SMHP</td>
<td>Monitoring/follow up takes place in various places and by various professionals. Most within the memory clinic but also in CMHT’s and OPC</td>
<td>East/West</td>
</tr>
</tbody>
</table>
### Carer Support

- Carer packages
- Carer support services
- Carer Schemes

<table>
<thead>
<tr>
<th>Service Area</th>
<th>Name of Service</th>
<th>Provider</th>
<th>Detail</th>
<th>Geographical Area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flexible Respite Project</td>
<td>Suffolk Family Carers</td>
<td>Pays for employed carers from Crossroads, private care agencies or informal private arrangements to provide care at home to the person being looked after. April-August 08: 115 Family Carers looking after someone with some form of dementia (nb – this may include some with a perception of dementia) Flexible Respite Project April–Sept 08 115 out of 361 family carers (31.9%). These are figures from April 2008 from the flexi respite project at Suffolk family Carers - you need to bear in mind that some of these family carers supported may be caring for someone with what they feel is dementia but may not be a confirmed diagnosis as they carry out prevention work as well as support for eligible families</td>
<td>Countywide</td>
<td></td>
</tr>
<tr>
<td>Crossroads Caring for Carers (Waveney)</td>
<td>Crossroads Caring for Carers</td>
<td>Offers traditional ‘in the home’ care services</td>
<td>Waveney</td>
<td></td>
</tr>
<tr>
<td>Respite – bed based</td>
<td>Adult Care Services</td>
<td>Carers support worker</td>
<td>West</td>
<td></td>
</tr>
<tr>
<td>The Cedars and Crossroads</td>
<td>Alzheimers Society</td>
<td></td>
<td>Lowestoft and Waveney areas.</td>
<td></td>
</tr>
<tr>
<td>CMHT Social Services Alzheimers Society</td>
<td>NWMH Foundation NHS Trust Waveney Alzheimers Society</td>
<td>Carers group once weekly, organised jointly by Memroy clinic nurse and the Alzheimers society. Care Circle at The Kings Centre Alzheimers society Monthly support meetings at The Arches and Centurion (Alzheimers society)</td>
<td>Great Yarmouth Area</td>
<td></td>
</tr>
</tbody>
</table>
### Service Area

<table>
<thead>
<tr>
<th>Treatment, care and support Drugs</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Primary Care</td>
</tr>
<tr>
<td>• Secondary Care</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Service Area</th>
<th>Name of Service</th>
<th>Provider</th>
<th>Detail</th>
<th>Geographical Area</th>
</tr>
</thead>
<tbody>
<tr>
<td>CMHT based at Carlton Court</td>
<td>BW LO</td>
<td>ASSD</td>
<td>Carers assessor based at Ferry House (Not dementia specific)</td>
<td></td>
</tr>
<tr>
<td>CMHT based at Northgate Hospital</td>
<td></td>
<td>NWMH Foundation NHS Trust</td>
<td>These services are not specific to Dementia Services. Linkworkers based in GP practices can often be the first point of contact. The secondary care services (CMHT) work from Carlton Court. They offer full CMHT services, including diagnosis, treatment and support. The teams consists of: 2x Consultant Psychiatrist 4.8 CMHNs 1.0 Support Worker 1.0 Occupational Therapist Social Workers</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Link worker service – Single point of access. Secondary care services (OPCMHT) at Northgate Hospital (Again not dementia specific), eligibility criteria applies. Office hours are 9am to 5pm. CMHT. As above offers full CMHT services, including diagnosis, capacity assessments, treatment, care and support. The team consists of: 1.6 Consultant Psychiatrists 1 Staff Grade 0.6 Psychologist 4.8 CMHN's 1 Memory Clinic Nurse/CMH 1 O.T. 2.0 Support workers 1 Team Leader/ASW 1.5 Social workers (Norfolk County Council personnel -Co-located)</td>
<td></td>
</tr>
</tbody>
</table>

Drug bill is £1,116,505 for the year 2006/7 for primary and secondary care.
<table>
<thead>
<tr>
<th>Service Area</th>
<th>Name of Service</th>
<th>Provider</th>
<th>Detail</th>
<th>Geographical Area</th>
</tr>
</thead>
<tbody>
<tr>
<td>DJ BW</td>
<td>Norfolk and Waveney Mental Health NHS Foundation Trust provide secondary mental health services to the Great Yarmouth and Waveney Area</td>
<td>NHS</td>
<td>1x12 bedded ward for organic assessment. 2x Consultant Psychiatrists for Lowestoft &amp; Waveney area. 1.6 Consultant Psychiatrists for Great Yarmouth Area (These consultants also cover the CMHT, listed above) CMHT (as above) for Waveney area. CMHT (above) for the Great Yarmouth Area Day Hospital offering 4 days per week organic care. Up to 25 places per day. Crisis response will become live on 13th Oct 2008, in the form of a CRHTT for older people in both the Great Yarmouth and Waveney areas. Neither Services at Carlton Court not GY has dedicated beds or services for Younger People with Dementia, however we do cater for this client group when necessary. All of these services are not solely for people with dementia with the exception of the assessment ward.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Westgate ward</td>
<td>SMHPT</td>
<td>Acute admissions ward (F/D) 18 beds (BD)</td>
<td>West</td>
</tr>
<tr>
<td></td>
<td>Chillesford Ward</td>
<td>SMHPT</td>
<td>Acute admissions ward (D) 13 beds</td>
<td>East</td>
</tr>
<tr>
<td></td>
<td>CMHT's</td>
<td>SMHPT</td>
<td>Age inclusive generic CMHT's (F/D)</td>
<td>6 teams (BSE, newmrk't &amp; Thetford, Sudbury &amp; Hav'hill, Suffolk Coastal, Ipswich, Central)</td>
</tr>
<tr>
<td></td>
<td>Mhicop</td>
<td>SMHPT</td>
<td>Crisis Intervention and home treatment for older people (DF)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mental Health Intermediate Care</td>
<td>SMHPT</td>
<td>Intermediate Care for people with dementia, age inclusive (D)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Redwald Day Treatment Unit</td>
<td>SMHPT</td>
<td>Day treatment unit/day hospital for older people (F/D)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Talbot Unit</td>
<td>WSH</td>
<td>Day Hospital, now reduced to only one nurse who undertakes medication monitoring for AcHEI’s</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Psychiatric Liaison</td>
<td>SMHPT</td>
<td>Nurse and staff grade? Providing liaison services to Ipswich hospital (F/D)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>YPWD - Commissioned with Age Concern</td>
<td>SMHPT</td>
<td>Team leader – 35 hours, Social workers – 40 hours CPN – 20 hours, Carer Support Worker – 20 hours</td>
<td>Countrywide</td>
</tr>
</tbody>
</table>
### Service Area
### Name of Service
### Provider
### Detail
### Geographical Area

<table>
<thead>
<tr>
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<th>Provider</th>
<th>Detail</th>
<th>Geographical Area</th>
</tr>
</thead>
</table>
|             | Acute activity  | Ipswich Hospital | Dementia  
- 28 admissions over 21 days LOS  
- total LOS: 1152 days average LOS: 41 days  
- 39 admissions under 21 days LOS  
- total LOS: 328 days average LOS: 8 days  
- 17 patients with no LOS  
Alzheimer’s  
- 10 admissions over 21 days LOS  
- total LOS: 402 days average LOS: 40 days  
- 9 admissions under 21 days LOS  
- total LOS: 99 days average LOS: 9 days  
- 4 patients with no LOS |
| West Suffolk Hospital | Dementia  
- 7 admissions over 21 days LOS  
- total LOS: 333 days average LOS: 48 days  
- 8 admissions under 21 days LOS  
- total LOS: 56 days average LOS: 7 days  
Alzheimer’s  
- 3 admissions over 21 days LOS  
- total LOS: 92 days average LOS: 31 days  
- 2 admissions under 21 days LOS  
- total LOS: 3 days average LOS: 1.5 days  
- 1 patient with no LOS |
| Addenbrooks | Dementia  
- 2 admissions over 21 days LOS  
- total LOS: 97 days average LOS: 49 days  
- 1 admission under 21 days LOS  
- total LOS: 10 days average LOS: 10 days |

<table>
<thead>
<tr>
<th>Accommodation</th>
<th>JL</th>
<th>Res Care - 2,109 Contracted b/spaces – (858 for dementia)</th>
<th>SC - 435 b/spaces 238 for dementia Nursing Home - 1,458 (Contracted b/spaces)</th>
<th>VSH – 97 in Extra Care; 624 in VSH YPWD – 6 (The Courtyard, Ipswich)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accommodation</td>
<td>JL</td>
<td>Res Care - 2,109 Contracted b/spaces – (858 for dementia)</td>
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<td>VSH – 97 in Extra Care; 624 in VSH YPWD – 6 (The Courtyard, Ipswich)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Others Res</th>
<th>EMI/ESMI/ Special needs Res</th>
<th>Others Nrs</th>
<th>EMI/ESMI/ Special needs Nrs</th>
<th>total Care Home</th>
</tr>
</thead>
<tbody>
<tr>
<td>1213</td>
<td>263</td>
<td>633</td>
<td>86</td>
<td>2239</td>
</tr>
</tbody>
</table>

#### Compass report at August 08
- SCOOP (Support Care of Older People)  
- Carewatch - Community Support service for Older People with Support Needs  
- SNAP - Support and Advice Project  
- Home Improvement Agencies (including Handyperson services)
<table>
<thead>
<tr>
<th>Service Area</th>
<th>Name of Service</th>
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<th>Detail</th>
<th>Geographical Area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respite</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day care</td>
<td>SCC - 12 registered with CSCI for Shortterm care Crossroads - see Carer support</td>
<td>NHS</td>
<td>Within the Continuing Care Wards there are two dedicated beds for respite care. Service users are assessed under the Continuing Care NHS eligibility criteria for suitability and Reviewed regularly. Referral must be made by secondary care mental health services. There are no NHS respite beds for those who do not meet the Continuing Care Eligibility Criteria.</td>
<td>Great Yarmouth and Waveney PCT</td>
</tr>
<tr>
<td>Crossroads</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Residential care</td>
<td>2 Respite Beds Carlton Court Norfolk and Waveney Mental Health NHS Foundation Trust</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nursing home care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>VSH</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>YPWD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day Services</td>
<td>Day Care</td>
<td>SCC In-house</td>
<td>256 special needs Compass – 1,259 receiving day care 41 EMI day services</td>
<td></td>
</tr>
<tr>
<td>Statuatory</td>
<td>Age Concern Chilton</td>
<td>Day service Mon –Fri (12 places available)</td>
<td>Sudbury</td>
<td></td>
</tr>
<tr>
<td>Vol Sector</td>
<td>Age Concern Jubilee Court</td>
<td>Day service Weds (9 places)</td>
<td>Halesworth</td>
<td></td>
</tr>
<tr>
<td>Lunch clubs</td>
<td>Age Concern The Links</td>
<td>Mon- Wed- Fri (12 places daily) (has capacity to open all week if demand identified))</td>
<td>Bury St Edmunds</td>
<td></td>
</tr>
<tr>
<td>Independent sector</td>
<td>Alzheimer’s Society</td>
<td>Once a month informal Sunday lunch</td>
<td></td>
<td></td>
</tr>
<tr>
<td>YWP D</td>
<td>YP WD</td>
<td>Carers lunch groups – varies according to need held in 4 geographical areas</td>
<td>Bury St Edmunds, Lowestoft, Ipswich and Sudbury</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sue Ryder</td>
<td>The Stables, Chantry House, Ipswich</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Currently there is limited access to Day Activities inGY due to lack of sufficient staffing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service Area</td>
<td>Name of Service</td>
<td>Provider</td>
<td>Detail</td>
<td>Geographical Area</td>
</tr>
<tr>
<td>---------------------</td>
<td>-----------------------</td>
<td>------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------</td>
</tr>
</tbody>
</table>
| Social care         | Compass report        | MHA                    | OP MH Social Work Team; 1 Senior Prac; 3.5 FTE SW 30 hrs SW – caseload capacity 91. (NB – not all caseload has dementia)  
West Suffolk Hospital SW Team snapshot - “Out of 303 allocations the average is 37% of people have dementia of some sort, diagnosed or not and maybe the primary condition or a secondary factor ie relatively mild dementia” | OP MH Social Worker Team - East             |
|                     | Aug 08 - 963 >10 hours| | | | Exning Court | Locator technology | West |
|                     | OP MH Social Work Team (see accommodation above) | | | | Levington Court | Locator technology | Waveney |
|                     | | | | | Rekindling Memories | Museum Loan boxes/ | | |
|                     | | | | | | Day care provided by ASSD in Rosewood and Riverview day centres for people with a dementia illness. Social Services funded Respite care also provided by ASSD in Magdalen House and Mildred Stone House. | ASSD |
| Home Help Services  | Age Concern Suffolk   | | Provides a limited service on demand | |
| ECRs                | BW LO                 | | 1 Possible placement pending – Private Hospital | |
|                     | | | | | | | |
| Continuing care     | Carlton Court         | NHS                    | 34 NHS Continuing Care Beds for people with dementia. These places are based on 3 x 12 bedded wards within Carlton Court. There are some younger people with dementia placed within these beds. | Beds are for the whole of Great Yarmouth and Waveney PCT |
|                     | Norfolk & Waveney     | | | |
|                     | BW LO                 | | | |
### Service Area

<table>
<thead>
<tr>
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<th>Provider</th>
<th>Detail</th>
<th>Geographical Area</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Homes contracted to take</td>
<td>Mental Health Foundation</td>
<td></td>
<td>Nurse and ?SPs who undertake reviews and assessments. Currently 21 people in the east with NHSCC. No figures available for the West as there is no comparable system. Placement is now in a variety of settings across the county.</td>
<td>Waveney PCT</td>
</tr>
<tr>
<td>• YPWD</td>
<td>NHS Continuing Health Care.</td>
<td>PCT/SMHPT</td>
<td></td>
<td>East</td>
</tr>
<tr>
<td><strong>Palliative Care</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Grants specifically for dementia related services</strong></td>
<td>BW JL LO</td>
<td>Lowestoft &amp; Waveney Alzheimer’s Society</td>
<td>Support and Training for People with Dementia and their Carers. (Single Gateway) (Prevention Grant???)</td>
<td>Waveney</td>
</tr>
<tr>
<td><strong>Advocacy services</strong></td>
<td>All</td>
<td>PALS (NWMH NHS Foundation Trust ESAN IMCA</td>
<td>Has an office on the site at Carlton Court, not dedicated for people with dementia and their carers.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>All</td>
<td>Age Concern Suffolk</td>
<td>3 Advocates working across County</td>
<td></td>
</tr>
<tr>
<td><strong>Voluntary sector services</strong></td>
<td>All</td>
<td>YPWD Team</td>
<td>Dedicated team working countywide with younger people and their families caseload currently of 70 clients integrated team with social workers and CPN has a Dementia Support Worker who plays a significant part in giving low level support to the client and their family.</td>
<td>Countrywide service based at Claydon</td>
</tr>
</tbody>
</table>
Transforming the quality and experience of dementia care for the people of Suffolk

**Complete Pathway**

**Dementia Care Pathway - Stage 1: Raising Awareness and Understanding**

### How Achieved

- Health Training
- Respite care (where appropriate) in sector: swimming pools, games etc.
- Enhanced public awareness: swimming pools, games etc.
- Marketing: co-ordinators, Assistant manager, sector: swimming pools, games etc.
- To wider variety of individuals: Rainbow Theatre, community events, community workers.
- **Health Advisors.**
- **Ph Advices.**

**WORKFORCE REQUIRED - all working to a set of core competencies**

- Use of drugs associated with dementia.
- NICE Group Supportive recommendations for.
- Advisory Services.
- Care Education and Support.
- Health Information (formation protection)
- Innovative education model for support workers.
- Diagnosis care sensitive teams/services.
- Training education and modules.
- Set of core standards.
- Role of carer.
- Early diagnosis, assessment and support.
- Immediate treatment.
- Support systems in place.
- Advice and guidance.
- Early identification.
- Dealing with all aspects.
- Services offer choice and respected dignity.

**Outcome Required - people are able to access any guidance of dementia and support**

### How Achieved

- Identifying elders, reducing the risk and effects of dementia.
- Enhanced public are better informed about dementia, reducing stigma and fear.
- People living healthier lifestyles reducing the risk and effects of dementia.
- **Informing and awareness campaigns.**
- **Schools.**
- **High Profile Case examples.**
- **Publish.**
- **NICE PH 16.**
- **Cardiovascular wellness programmes.**
- **NICE.**
- **GP and G PSI training.**
- **SW and all NH workers to have module on their training.**
- **OT and Physiotherapists (NH) providing supervision and support.**
- **MH liaison.**
- **NICE advice.**
- **Ph Advices.**

**DEMENTIA CARE PATHWAY - STAGE 2: EARLY DIAGNOSIS AND SUPPORT**

### How Achieved

- Early identification, assessment and accurate diagnosis.
- Informing and effective multi-agency, multi-professional workforce able to deal with all aspects of dementia.
- Immediate treatment (NICE guidelines).
- Information, maintenance, counselling and support system in place.
**DEMENTIA CARE PATHWAY – STAGE 3 MAINTENANCE AND DAILY LIVING WITH DEMENTIA**

**OUTCOME REQUIRED** - people living with dementia (and their carers) are effectively supported with the services they need, that offer choice and respect dignity

<table>
<thead>
<tr>
<th>Continuous ongoing support to carer and person with dementia.</th>
<th>Timely access to an integrated intermediate care team team in a crisis -</th>
<th>Enabled to remain independent and to live at home or their place of choice</th>
<th>If required acute admissions to general hospital a ‘good experience’ support throughout.</th>
<th>Supported and reassessed for discharge, creation of ‘specialist’ volunteers within welcome home team</th>
</tr>
</thead>
</table>

**HOW ACHIEVED**

- Generic case worker – dementia support worker.
- Buddy schemes.
- 24hr. rapid response to crisis – focus on admission prevention and enablement.
- Home first able to support dementia sufferers.
- Carer and cared for support groups.
- Wide awareness of and use of assistive technology.
- Specialist housing schemes.
- Liaison with specialist (in reach teams) Support workers encouraged to advise on care.
- Support through fully integrated health and social care teams including high percentage of joint funded generic workers.

**WORKFORCE REQUIRED** – all working to a set of core competencies

<table>
<thead>
<tr>
<th>Support worker NVQ’s.</th>
<th>Vol sector and stat services.</th>
<th>Carer groups.</th>
<th>Carer support –.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer counsellors.</td>
<td>Care in home flexible respite e.g. vol sector.</td>
<td>Specialist day services, drop in centres, dementia clubs.</td>
<td>Home care workers trained in dementia care.</td>
</tr>
<tr>
<td>Respite activities.</td>
<td>Maximise use of self directed payments.</td>
<td>Hospital liaison services.</td>
<td>Raised awareness of the needs of people with dementia in all care settings.</td>
</tr>
<tr>
<td>RMN added to all ICT and rehab teams.</td>
<td>ICT staff equipped to deal with physical and dementia needs of the client.</td>
<td>Practice nurses and nurse practitioners trained in dementia care and support.</td>
<td>Specialist housing officers.</td>
</tr>
<tr>
<td>Assistive technology technicians.</td>
<td>Volunteers experienced and trained in dementia care and therapy.</td>
<td>Sitters trained to care for people with dementia.</td>
<td>All staff trained across sectors in basic assistive technology assessment.</td>
</tr>
<tr>
<td>Group leaders specialising in dementia.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**DEMENTIA CARE PATHWAY – STAGE 4 CRISIS AND END STAGE**

**OUTCOME REQUIRED** - people living with dementia (and their carers) have access to effective services in a crisis; services at the end of life support people living with dementia (and their carers) to make choices, and also respect their dignity

<table>
<thead>
<tr>
<th>Carer and person with dementia receiving the level of care required to enable them to live at home</th>
<th>Intermediate care schemes for escalating crisis support - high level</th>
<th>Short term admission only when required to MH services specifically able to cope with the needs of someone with an organic illness</th>
<th>Continuing care needs assessed and met</th>
<th>Variety of suitable care schemes available to enable the carer and cared for to experience death with dignity in the place of their choice</th>
</tr>
</thead>
</table>

**HOW ACHIEVED**

- Ongoing support from dementia support worker.
- 24hr. rapid response to crisis – focus on admission prevention and enablement.
- Community care available to standards required to meet the needs of people with dementia.
- Community support available and open to people with dementia.
- Support through fully integrated health and social care teams including high percentage of joint funded generic workers require both MH and generalist skills.
- All normal palliative care services available and able to cope with end of life care for this client group.
- Wards geared up for short intervention, staff versed in risk management and independence community team involved in discharge as per community matron type model. | Carer groups to provide peer support. | Nursing homes providing care to an agreed standard. | In reach liaison from MH teams. | Hospice at home type care. |
### GROUPS FOR SPECIAL CONSIDERATION

**OUTCOME REQUIRED** - services respect the diversity and different needs of all groups within society

<table>
<thead>
<tr>
<th>Services able to adjust to meet needs black and ethnic communities</th>
<th>Services to Prisoners with dementia</th>
<th>Working Age Adults</th>
<th>Services to people with Learning Disabilities</th>
<th>Services to minority communities</th>
</tr>
</thead>
</table>

### HOW ACHIEVED

- In principle all of the communities above will receive the same core services as described on the previous pages of this document but tailored to the specific requirements of the client group.
- The Mental State Assessment scoring system for example needs to be able to be modified for Asian communities.
- Carer support options need to consider the cultural requirements on ethnic communities and provide choice to meet the needs of these carers.
- Separate strategy to be developed for working age adults.
- Needs to incorporate MH capacity Act and Safeguarding Adults.

### WORKFORCE REQUIRED – all working to a set of core competencies

- Recruitment of the Dementia Support Workers should positively seek to employ multi ethnic workers.
- Training for all staff should specifically include the needs of ethnic and minority groups.
- Prison staff should have core training in dementia and managing cognitive impairment.
If you would like a short summary of this document, or the whole document translated into another language, please ask an English-speaking friend to contact us on 01473 770014.

Se pretende obter um pequeno resumo deste documento, ou caso pretenda que todo o documento seja traduzido para outro idioma, por favor peça a um colega que fale Inglês para nos contactar através do número 01473 770014.

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