

An overview of community services for people with dementia in rural Suffolk, Cambridgeshire and Norfolk

Identifying what services are available and/or are used by older people with dementia living in rural communities is extremely complex. Many of the services used by this group are not specialist services identified for them but general and/or informal. Finding out about how people gain support to live at home would only be possible by gathering data on an individual by individual basis - an undertaking which this study did not have sufficient time to tackle.

Many services for older people and older people with mental health needs are currently in a period of transition with this area being highlighted by the government as a priority area. Structures are changing with the drive towards social and health services working more closely together. Partnership mental health agencies have been set up in all 3 counties who are looking at new models of working and delivering services.

An overview is given here on service provision in rural areas, including market towns. It does not include information about the services that may be available in the county's cities or secondary care provision. Nor does it include details of the extra care or housing with care schemes that are emerging across the region as alternatives to residential care.

*Data were gathered primarily through research interviews with the participants detailed in the **Methodology** section of this report. Further information was obtained from documents submitted by agencies and others which were available publicly, either via the internet or directly from the agency concerned. The description of services below is not intended to be exhaustive but to provide an overview of the types of services currently available in each county.*

Areas

Suffolk

Suffolk is divided by many agencies into 2 key areas:

- East Suffolk covers the central belt of mid-Suffolk as well as the coastal strip. It covers the towns/cities and areas surrounding: Ipswich, Saxmundham, Kesgrave, Stowmarket, Felixtowe, Eye, Hadleigh and Shotley. For statutory services, the northern part of the Suffolk Coast, the area surrounding Lowestoft is managed by Norfolk Social Services, Norfolk and Waveney Mental Health Partnership Trust and Great Yarmouth and Waveney PCT. However, several Suffolk based voluntary and independent agencies provide services to this area.
- West Suffolk is centred on Bury St Edmunds but also covers the towns and areas surrounding: Sudbury (West Suffolk Hospital),

Haverhill and Newmarket. Some statutory services are also delivered to Thetford and surrounding areas in Norfolk.

Cambridgeshire and Peterborough

The Cambridgeshire and Peterborough area is divided into the following areas by the majority of agencies providing services for people with dementia:

- Peterborough
- Huntingdonshire
- Cambridge City & S.Cambs
- E.Cambs & Fenland.

Norfolk

Norfolk is divided by many of the agencies working there into 3 key areas:

- West Norfolk (covering Kings Lynn and surrounding areas)
- Central Norfolk (covering Norwich and the areas north and south of the city stretching to the coast in the north and the Suffolk border in the south)
- Great Yarmouth (covering the town and surrounding areas)

As described above, for statutory services, a 4th area exists which is usually referred to together with the Great Yarmouth area. It is the Waveney area which includes and surrounds Lowestoft and is actually part of Suffolk. Historically this area has been managed by Norfolk statutory services.

Statutory service management

Suffolk

Suffolk has 5 Primary Care Trusts: Ipswich, Suffolk Coastal, Central Suffolk, Suffolk West as well as Waveney PCT which is part of Norfolk's NHS services.

Social Care Services recently reconfigured their services around PCT areas and social care staff are board members of the PCTs.

Local Health Care Partnerships NHS Trust and Suffolk County Council Social Care Mental Health Services recently formed a new partnership organisation: Suffolk Mental Health Care Partnership NHS Trust. This organisation currently delivers services to working age adults but has been instrumental in developing an Older People's Mental Health Strategy and "*may develop to include OPMH services at a later date*" (Older People's Mental Health Strategy for Suffolk, Draft, 17.01.05, p8). The adult services part of the trust is integrated with the local authority but older people's services are currently only health with social services provision operating separately.

Cambridgeshire and Peterborough

Peterborough and its surrounding areas forms a separate unitary authority to Cambridgeshire. In April 2004, the Adult Social Care Department of

Peterborough City Council integrated with North and South Peterborough Primary Care Trusts to form the Greater Peterborough Primary Care Partnership.

At the same time in Cambridgeshire, older people's social care staff were re-deployed to the PCTs: Huntingdonshire PCT, Cambridge City & S.Cambs PCT and E.Cambs & Fenland PCT.

Cambridgeshire and Peterborough Mental Health Partnership NHS Trust provides specialist mental health services for older people across the whole area. Specialist services are commissioned from the Mental Health Partnership by the PCTs.

Norfolk

Norfolk is covered by six Primary Care Trusts: Norwich, Broadland, North Norfolk, South Norfolk, West Norfolk and Great Yarmouth & Waveney.

The Norfolk and Waveney Mental Health Partnership NHS Trust delivers mental health services across the county except for the Kings Lynn area. Here services are provided by West Norfolk PCT.

Norfolk Social Services provides social care services to older people with mental health problems and their carers through Older People's Services. Each PCT area has a Social Services District Manager who sits on the PCT board and is responsible for commissioning services in that locality.

Older People's Mental Health Strategies and Groups

Detail is given here of the strategies and groups that were publicly available or made available to the research team by agencies through interviews. More detail is therefore given in some areas than others which should not necessarily be interpreted as a lack of strategic direction in some areas but a lack of information about it available publicly.

Suffolk

Social Care in Suffolk were asked by social care inspection to produce a strategy for older people's mental health services. The resulting strategy was very much aligned to an older peoples mental health strategy (see case study) development process also being undertaken by Suffolk Mental Health Partnership NHS Trust. In the West of the county, groups developed through the NSF process and as offshoots from an Older People's Modernisation group, have helped to push this process forward, looking at management arrangements, assessor roles within social care service, how services fit into needs of Mental Health strategy. There is however, an inevitable tension between locality and county wide needs which have to be addressed as part of this process. A sub-group of the Older People's Modernisation group exists in the west of the county which is looking particularly at mapping of issues and needs in terms of service deficits other than beds.

CASE STUDY: Suffolk's Draft Older People's Mental Health Strategy

Originally launched in 2003, this strategy is being developed to look at service needs and development across the whole of Suffolk. It aims to set out a "jointly agreed set of priorities for the development of specialist services that is accessible to anyone who wants to help improve services, and should be built upon our local experiences and expertise" (Older People's Mental Health Strategy for Suffolk, Draft 9 – 17.01.05 Page 3 of 51).

The strategy aims to be realistic in its goals rather than idealistic and to build upon what already exists and partnership working with a range of other services both specialist and general in order to improve provision for older people with mental health issues.

It has been recommended that a high profile, multi-agency group and implementation team is established in order to maintain the status of older people's mental health in Suffolk and to ensure that the ideas contained within the strategy are delivered.

Cambridgeshire and Peterborough

A written strategy for Older People was not available from Cambridgeshire Social Services. At the time of this research Social Services had just completed the re-deployment of older people's personnel to PCTs.

Section 3 of the Cambridgeshire and Peterborough Mental Health Partnership NHS Trust's operational objectives covers Older Peoples' Services. Included here is an aim to ensure that access to services are needs related rather than age related by 2006 and a drive towards full integration with a single assessment process that includes use of CPA and Care Management.

Peterborough has a "Strategy to Support the Mental Wellbeing of Older People".

Norfolk

Norfolk Ambition – The Community Strategy for Norfolk 2003-2023 was developed by Norfolk Strategic Partnership which was formed in response to The Local Government Act 2000 (Norfolk County Council, 2004, p4). It focuses on improving the quality of life for all people in Norfolk by the year 2023.

In 2004, Norfolk Social Services produced The Norfolk Older People's Strategy – Living Longer, Living Well (See case study: Norfolk Older People's Strategy), in collaboration with other agencies working with older

people in Norfolk and based on feedback from a wide variety of sources. It was intended as a starting point and inspiration for the development of older people's services in Norfolk. It is hoped that it will lead to the development of a "Charter of Rights" for older people living in Norfolk (Norfolk County Council, 2004, p2).

CASE STUDY: Norfolk Older People's Strategy: "Living Longer, Living Well"

Norfolk's Older People's Strategy was published in October 2004. It originally grew out of discussions around planning for Norfolk's residential homes and the need for a broader context in which to situate these discussions.

The work was led by Social Services but involved a large number of partner agencies and stakeholders including Primary Care Trusts, Norfolk Age Concern, Alzheimer's Society and the Independent Sector. A broad consultation was carried out across these groups in order to gather information about priorities and issues for older people living in Norfolk. It seeks to inform not only specialist service provision but also how older people's needs are incorporated into all key services.

The key themes covered by the strategy are:

- Social Inclusion and Engagement
- Maximising Income
- Information/Advice and Advocacy
- Housing and the home
- Leisure and Life Long Learning
- Safety and Security
- Accessing Community Services
- Social Care
- Health Services and Social Care Interface

(Norfolk County Council, 2004, p2)

In addition to its broad themes which have relevance for all older people in Norfolk, detail is also included about Mental Health Services for Older People. Here, a shift away from inpatient services towards the provision of services in the community is discussed along with the structures and services that are needed to achieve this (Norfolk County Council, 2004, p141).

Implementation of aspects of the strategy has begun. However, it is acknowledged that the time frame for the implementation of different parts of the strategy will vary from area to area and depends to a large extent on local adoption of the overall themes of the document. Steering groups have been set up to oversee much of this work and to set time frames and agendas for implementation (Interviewee, Norfolk Statutory Services).

Norfolk Health and Social Services Local Delivery Plans based on Norfolk's PCTs set out key performance indicators and national targets to be achieved by 2006. They focus on "improving service capacity to enable people to be supported at home" (Norfolk County Council, 2004, P45).

Local Strategic Partnerships exist in different areas of Norfolk. In some areas, sub-groups focus on older peoples issues and implementation of the National Service Framework for Older People.

In Great Yarmouth, the National Service Framework Local Implementation Team for Older People is made up of representatives from statutory and voluntary agencies in the area and is instrumental in planning and developing services. Other groups focusing specifically on Older People's Mental Health include: Older Peoples Mental Health Steering Group, Great Yarmouth Older Peoples Mental Health Steering Group, Great Yarmouth and Waveney Older Persons Strategy Group. (Norfolk County Council, 2004).

West Norfolk PCT is working with Social Services towards partnership agreements around the single assessment process. They have also recently modernised their specialist mental health service for older people (Norfolk County Council, 2004). There are also groups looking at Intermediate Care and Older People's Mental Health which link into county wide groups.

Central Norfolk, covered by Norwich, Broadland, North Norfolk and South Norfolk PCTs along with the Acute Trust, Mental Health Trust and Social Services together have a collaborative partnership to deliver a plan called "Better Care for Norfolk". The plan includes a number of service improvements and focuses on admission avoidance, chronic illnesses, community services and seamless working across organisational boundaries (Norfolk County Council, 2004).

At the time of writing, Norfolk and Waveney Mental Health Partnership Trust were undergoing the consultation phase of their strategy "Continuing to Care – Looking after older people with mental illness in Central Norfolk" (2005). This strategy is working towards the closure of various long stay wards and beds across the area and the introduction of a number of new specialist services. These would include increased numbers of specialist mental health staff working in community settings, a specialist crisis support service and the development of a Dementia Intensive Care Unit. Older people's services will join those for working age adults to form new locality mental health services for both groups. Specialist services would be provided according to need rather than age.

Joint strategic work being carried out by Social Services, the Mental Health Partnership and voluntary agencies focuses on people receiving specialist input in the community.

Norfolk Carer's Action Plan 2005-2008 was produced in January 2005 by the Norfolk Carers Partnership, made up of Norfolk County Council,

Norfolk Health, Carers, Voluntary Agencies and the Department of Work and Pensions (see case study).

Community Teams

West Suffolk

There is one older people's social work team in the west of the county which is hospital based. Within the team are 2 specialist mental health social workers who are attached to the Wedgwood Unit and work with the older person's NHS mental health team. They are not official members of the team but work closely with it. However, the majority of people with dementia living in the community are dealt with by the generic locality teams with the specialist workers being more involved with cases that require hospital admission/discharge or are of higher profile (Interviewee, Statutory Services, Suffolk).

There are 5 NHS older people's community teams within the area, 4 of which are co-located with the adult community teams (Interviewee, Statutory Services, Suffolk). All visits are operated through the care programme approach, focusing on person centred care. The teams have a variety of relationships with social care locality teams from commissioning care only through "customer first" to direct referral to a named social worker by having social workers attend case meetings. Psychological input is limited due to staff shortages and focuses on psychological awareness amongst CPNs and supervision of CPNs carrying out psychological therapies (Interviewee, Statutory Services, Suffolk).

The integrated social care/health MHICOP team (Mental Health Intermediate Care Team) has existed for the last 2 years to provide short term intervention focused on admission avoidance for older people with mental health needs. It will only accept referrals from consultants (see case study)

CASE STUDY: Suffolk Mental Health Partnership, MHICOP Team

The integrated social care/health MHICOP team (Mental Health Intermediate Care Team) has existed for the last 2 years to provide short term intervention focused on admission avoidance for older people with mental health needs. Its objectives as stated in Suffolk Older People's Mental Health Draft Strategy are:

- to provide intensive and/or crisis care in order to prevent unnecessary hospital admission or facilitate earlier discharge
- to reduce pressure on in-patient beds, reduce average length of stay and delayed transfers of care
- to ensure smooth transition between different services facilitating a seamless service to the client
- to give support and advice to staff and managers working in other care settings enabling the person to remain within their place of residence and to facilitate a smooth transition of care at the point of discharge

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- to provide time limited specialist care to people in their own homes following discharge to facilitate ongoing rehabilitation

(Older People's Mental Health Strategy for Suffolk – Draft – 17.01.05)

The MHICOP team is widely regarded as being extremely successful in achieving its remit to provide short term timely interventions for older people with mental health problems and their carers where there is some sort of crisis. It has achieved reduction of admission rates of around about 30%. (Interviewee, Suffolk Statutory Services)

It has been described as "*bringing the institution, the people part of the institution to people's homes*" in order to prevent admission to hospital. It uses innovatory methods of supporting people though crisis periods such as breakdown in carer support or flare up of symptoms. These methods do not involving admitting people to hospital but focus instead on providing specialist and intensive support in people's homes.

East Suffolk

There is an older person's mental health social work team that is based at Ipswich hospital in the same building at the CPN team though not jointly managed. The MHICOP team (Mental Health Intermediate Care Team) is also based here.

The majority of dementia cases in the community are dealt with by the locality social work teams and community mental health teams. There is no integration between social work and health with health teams using a central number to access social work (Bedford, 2004). Age Concern multidisciplinary ACCESS teams (see case study) operate with limited patches from Stowmarket (early onset dementia), Ipswich and Halesworth (mainly into Waveney) and are able to organise and manage health and social care services although those with complex psychiatric problems tend to be referred to specialist mental health services (Bedford, 2004).

CASE STUDY: Age Concern Suffolk – Access Teams

Age Concern Suffolk manages 3 multidisciplinary teams in Suffolk for people with dementia and their carers. They are small teams which employ Social Workers, Community Psychiatric Nurses, Community Support Workers and Community Care Practitioners. They would like to also employ Occupational Therapists. Each team member has access to clinical supervision from a representative from their own discipline from Statutory Services as well as being managed day-to-day by an onsite team manager. They are funded by the PCTs and Social Services and work with approximately 350 people at any one time.

These people are drawn from very specific areas:

Ipswich Team – covers only Ipswich

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Halesworth Team – this is a particularly rural patch with the team covering a range of villages and hamlets located in a 15 mile radius of the small market town of Halesworth.

Stowmarket – covers the whole county but only those people who are under 65 years of age with early onset dementia.

All the ACCESS teams operate an open referral process whereby people can self refer, refer a neighbour or friend or, more commonly be referred from statutory agencies. The team provide a “one-stop shop” for people and cases are kept open for as long as clients need the service; one of the key philosophies of the teams is not to close cases though people will be signposted where relevant to more specialist services but with the ACCESS team still available as a contact point if appropriate. Typically cases open due to a crisis point being reached in the client’s life – for example a suspicion of or a recent diagnosis of dementia, a break down in network of care etc. Once clients have been supported through this crisis period, a case may then stay “dormant” for a lengthy period of time but the ACCESS team will maintain periodic contact using a “call back system” to check that people are okay. This period may then be followed by a further crisis period where a higher level of support is required by the team. The Community Support Workers in the teams focus on providing short term intensive support during crisis periods.

Many individuals and their carers are supported right through from before first diagnosis, through a period of living at home at the end of which they may be supported by the team to identify suitable residential or EMI care.

For individuals who are publicly funded, the review process then typically moves over to Statutory Services once the carers and individual are satisfied that the client is in a suitable placement. However, it is always made very clear to the carers that they can return to the ACCESS team at a later date if they feel they require further support. For individuals who are privately funded, the ACCESS team will continue to carry out reviews. They would look particularly at the individual’s ongoing financial status and whether they required public funding.

The initial assessment carried out by the team is broad and incorporates Social Services paperwork. It gives an in-depth look at the needs of the client and includes information about their background and interests/occupation, family life etc. A carer’s assessment is also incorporated looking at the “network” of care that the individual has access to - this may include a key carer (husband or child for example) as well as a range of other informal carers like neighbours, friends and/or groups that the individual belongs to.

The teams work closely with their local statutory sector colleagues with more complex cases being signposted to specialist statutory services.

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Care packages are set up in partnership with social services colleagues and are managed by the ACCESS teams.

With funding from the Carer's Grant, the Halesworth Team runs regular Carer's Support Groups in addition to their other services. These groups provide opportunities for people with dementia and their carers to gain support from one another.

The Stowmarket Team provides an innovatory service for people with early onset dementia which is unique to Norfolk, Suffolk and Cambridgeshire. It is the key agency providing services to this group in Suffolk and the only agency that specialises in services to this group. It is run on a similar model to the other ACCESS teams and can provide specialist information and support to this client group and their carers.

In 2003-2004, "Breakaway" was set up by the team in the Younger People with Dementia Team in partnership with West Suffolk Crossroads, with support from the Carer's Grant. This club is for the ACCESS team's clients which provides respite for carers though carers are often keen to join in gaining valuable peer support from one-another in a supportive setting where they know their loved ones are being cared for.

Clients also access the S.P.A.C.E project, managed by Lowestoft Alzheimer's Society and supported by a carer's grant which offers 1:1 support with pursuing hobbies, interests and maintaining skills.

Cambridgeshire and Peterborough

Integrated locality teams (ILTs) composed of social workers, nurses and OTs provide community services to those living in their own homes. These teams are employed and managed by the PCTs and deal with the majority of dementia cases in the community.

For people with more complex mental health issues, services are provided in partnership with, or solely by specialist older people's mental health teams employed by the Mental Health Partnership covering the 4 localities.

Further details about the Older People's Community teams can be found in Dr Susan Bedford's research study: Community Teams for the Elderly with Mental Health Problems (NIHME, Bedford, 2004). Teams were surveyed in 2004. At this time, 6 community mental health teams were operating in the area for older people, 4 of which had achieved full integration. The team in Huntingdon was described as "approaching functional integration" and the team in East Cambridgeshire was described as having "no integration" – ie there were no regular meetings between the team and social work staff with referrals being made through a call centre and/or via a care manager.

Over the last year since this study was carried out, teams have steadily progressed their levels of integrated working and despite problems around suitable accommodation for teams and compatibility of IT systems are now operational as integrated teams (see Case Study).

CASE STUDY: Integrated Teams in Cambs and P'boro

Cambs and P'boro is unique in the area in having a county wide system of integrated social and health care teams (both generic and specialist) that are managed by a single line manager. These teams have their origin in integrated social and health care teams that existed in the county more than 15 years ago. When Cambridgeshire and Peterborough Mental Health Partnership was set up in 2001, there was a drive, particularly from users and carers, to integrate services with Social Services in order to create as seamless as service as possible for people using it.

In April 2004, the Adult Social Care Department of Peterborough City Council integrated with North and South Peterborough Primary Care Trusts to form the Greater Peterborough Primary Care Partnership. At the same time in Cambridgeshire, older people's social care staff were re-deployed to the PCTs: Huntingdonshire PCT, Cambridge City & S.Cambs PCT and E.Cambs & Fenland PCT. Integrated Locality Teams composed of social workers, district nurses and OTs now provide community services to those living in their own homes. These teams are employed and managed by the PCTs.

A specialist older people's mental health team managed by Cambridgeshire and Peterborough Mental Health Partnership NHS Trust was piloted in Cambridge City for one year (2003-4) before being rolled out to the other areas. The team worked on the operational policy with the PCT to agree how services would be commissioned. The pilot was generally held to be a useful process which helped to iron out many of the "teething problems" with policy and procedure before the teams became operational on a wider scale, the most significant of which proved to be IT and the need for health and social care staff to account for how their time and funding is spent in different ways (Interview Transcript, Ass Dir, Camb and P'boro MH Partnership NHS Trust, Camb City and S.Camb).

The team in Cambridge City is now is now *"more or less identical to the NIHME checklist for integrated teams"* (Project Officer, Older People's Services, Cambridgeshire Social Services, Interview Transcript).

The other teams are at various stages of development with some teams still waiting for premises that will house the entire team in one location, an aspect of integration which is felt by many to be particularly important (Project Officer, Older People's Services, Cambridgeshire Social Services, Interview Transcript). However, they all have a single line manager and use integrated paperwork with CPNs and OTs carrying out social care assessments. All the staff in these teams use CPA. They also have team

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 support workers to assist with day to day monitoring including monitoring of medication (Bedford, 2004).

These specialist teams are small and as such tend to deal with the more complex cases with the majority of people with dementia living in the community being seen by Integrated Locality Teams (Project Officer, Older People's Services, Cambridgeshire Social Services, Interview Transcript). In some areas robust criteria have been agreed for access to the specialist teams, in other areas these are still in the process of being developed, using the Cambridge pilot team's experience as guidance.

In general it is felt that a fairly good relationship exists between the PCTs and Mental Health Partnership who manages the specialist teams. Staff have a good working understanding of referral criteria and referrals can be negotiated on a patient by patient basis (Interviewee, Cambridgeshire Statutory Services). In general it is the degree of complexity of the individual case which will determine whether a referral is made to the specialist team. In some cases a member of the specialist team may carry out some joint work with the primary care team in order to provide support and guidance in how to approach aspects of an individual's case.

Norfolk

NHS community mental health teams operate in: Kings Lynn and West Norfolk, South Norfolk, Great Yarmouth, North Norfolk and Broadland, Norwich City and Waveney. In some of these community teams there are nurses who have specialist skills in supporting people with dementia though there are no specialist posts for this client group (Interviewee, Norfolk Statutory Services).

In terms of integration with Social Services:

- Kings Lynn and West Norfolk have health and social care staff working in the same team from the same base
- South Norfolk, North Norfolk and Broadland, Norwich City, and Waveney (except Lowestoft) have functional integration with Social Services by having a regular meeting with a social worker who is allocated to the team
- In Great Yarmouth and Lowestoft there are no regular meetings of the team and Social Work Staff

(Bedford, 2004)

Community support worker roles are currently being examined as part of a rationalisation of specialist skills within teams. There is a drive towards investment in unregistered staff to support the community teams (Interviewee, Norfolk Statutory Services).

Domiciliary Care Services

Suffolk

There is a social services in-house service which provides some generic domiciliary care. A recent review of home care services has proposed that the in-house service should be renamed Suffolk Home First and would provide an initial 12 weeks of re-ablement services focused on eliminating need. After this period, care packages would be provided by the independent sector. This process began in April/May 2005 with initial re-ablement packages of care being provided to several clients (Interviewees Suffolk Statutory Services).

In West Suffolk independent sector home care services are insufficient to meet need whereas in the East of the county 2 thirds of home care services are under block contract to the independent sector (Interviewees Suffolk Statutory Services).

In West Suffolk, there is an intention to upgrade to a specialist dementia care home care service which would operate out of a new resource centre based at Glastonbury Court in Bury St Edmunds (see case study).

CASE STUDY: Development of Glastonbury Court, Bury St Edmunds, Suffolk

Glastonbury Court currently operates as a residential and nursing care unit. It is located in Bury St Edmunds.

Glastonbury Court is unique within West Suffolk in that it provides a mixture of Frail Elderly and Elderly Mentally Ill beds in its residential and nursing care services. Its manager is a recognised expert in the field of dementia care (Interviewee, Suffolk Statutory Services). It is proposed that the specialist dementia care element of Glastonbury Court will be expanded with an increase in the number of Elderly Mentally Ill beds available alongside a range of other services. These will include a new assertive outreach type of domiciliary care that will provide specialist outcome based services to people with dementia living in the community as well as day services. The site will be used as a venue for joint work with other agencies such as the Alzheimer's Society to provide individualised person centred services for people with dementia.

Cambridgeshire and Peterborough

Domiciliary services are currently provided largely by the independent sector. There is a small in-house (social services) service but this is used mainly for intermediate care and people with physical rather than mental difficulties. There is a drive towards developing a dedicated home care service for people with mental health issues which, it is felt would enable the maintenance of people in their own homes for a lot longer (Interviewees, Cambridgeshire Statutory Services). In Peterborough, home care is provided by Greater Peterborough Primary Care Partnership and the independent sector.

Norfolk

Domiciliary Care Services are provided by independent agencies and a Social Services in-house service. Social Services are currently working to modernise the in-house service with changes to staff contracts and management structure. They are moving towards a re-ablement service with intensive input offered for the 1st 6 weeks of care. They are also developing ideas around a specialist service for people with dementia (Interviewees, Norfolk Statutory Services). A Domiciliary Care Steering Group exists to modernise, promote and develop change. This is made up of representatives from the statutory and independent sector.

Support for Carers

Suffolk

Suffolk Carers provides services for carers and in particular can assist carers to access the grant funding to which they are statutorily entitled (see Case Study). They carry out in-depth assessments of individual carers needs which are made available to Social Services and they encourage and book people in for their statutory Carer's assessment.

CASE STUDY: Suffolk Carers

Suffolk Carers provides services to carers of older people with dementia through its generic team. They also refer people to the Alzheimer's Society branches for more intensive specialised support. Suffolk Carers is able to provide carers with a range of services including:

- Flexible Respite Project – this service is funded by the carer's grant and is for people over the age of 65. It provides respite services over and above what is provided by Social Services. Each person is eligible for a grant which can be used to purchase additional respite flexibly, often at short notice and through a range of providers.
- Carers into learning – this service is funded by the EU Social Fund and is available only to women. It provides a 6 session course focused on skills which will enable a person to re-enter the workplace.
- Carers into Education – this is funded by the carer's grant. Individuals are each entitled to a grant which can be spent on classes, transport, materials and respite

Services are also available to assist with manual handling and fire safety and Support Workers cover different areas of the county providing assessments and support for carers. Referrals are accepted from a wide range of agencies and people can also self refer. All cases are kept open for as long as people want them to be.

Support workers carry out a thorough assessment at an initial home visit a copy of which is provided to Suffolk Social Services. It covers a wide range of issues including:

- access to respite – checking statutory provision as well as linking

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 people in to additional respite through the flexible respite scheme described above

- transport and mobility
- daily tasks – looking at what help the carer is currently receiving, what their statutory entitlements are etc. Also, looking at access to direct payments where appropriate.
- housing issues – sometimes clients are referred to agencies such as the Hanover Trust which can facilitate access to the Disabled Facilities Grant.
- financial benefits
- carer's own health – may refer to an OT to assess safety within the home etc.
- wider family support
- education and employment opportunities
- holidays and leisure – can provide assistance with funding for holidays through charitable trusts, funds and grants
- plans can be put into play in the event of the informal carer being unable to continue caring for a period
- emergency planning – research by Carer's UK "Back me up" demonstrated a need for emergency planning systems for carers to put their mind at ease. Suffolk Carers is currently lobbying local authorities to set up a scheme whereby pre-prepared emergency
- hardship - provide referrals to a grant scheme that is available to cover the cost of various items and services
- befriending services – Suffolk carers runs support groups for carers and will make referrals to specialist support groups – eg those run by the Alzheimer's Society or to Age Concern's "Local Link".

This assessment does not however constitute the full carer's assessment to which carers are legally entitled. This is then carried out by statutory agencies. Suffolk Carers very much encourage the take up of these assessments and will book people in for them using Social Service's "Customer First" line.

Suffolk Carers also has a carer's resource centre which provides information and a workshop space, courses for carers, complementary therapies, 1st aid and relaxation.

A large number of Suffolk organisations are signatories to the Suffolk Carer's Charter which grew out of "The Mental Health of Carers", a paper published by the Suffolk Health Alliance Mental Health Focus Group in 1995.

Both the Alzheimer's society branches and Age Concern ACCESS teams provide 1:1 and group support and advice for carers.

Cambridgeshire and Peterborough

In Cambridgeshire, support for carers of people with dementia is provided by Alzheimer's Society Branches whose outreach workers provide group and 1:1 support. Various innovative projects have been set up by this

agency including a buddying system for carers in and around Ely (see case study).

CASE STUDY: Alzheimer's Society, Ely Branch – Carer's Buddying Scheme

The Ely branch of the Alzheimer's Society has developed an innovatory system of matching families of people with dementia and encouraging "buddying". Families and/or individuals within families are introduced by the branch workers in the hope that an informal system of mutual support will develop. Branch workers have an indepth knowledge of their clients and are skilled in matching people with similar interests and backgrounds. This system has worked so far for over 60 clients. The benefits of this type of support are its informality and shared experience which engenders trust and willingness to take on advice and support. It works particularly well in the rural areas with clients being encouraged to phone each other for support on a regular basis

The Huntingdonshire Branch of the Alzheimer's Society have designed and piloted a course for carers in partnership with statutory services (see case study). A Carer's Education Programme also runs in Cambridge twice a year covering a wide range of topics and designed specifically for carers looking after a relative with dementia at home.

CASE STUDY: “Caring with Confidence”, Alzheimer’s Society, Huntingdonshire Branch

“Caring with Confidence” is a locally run course for anyone who is a carer of a person with memory loss or dementia. The course is made up of 3 parts:

1. Getting started – made up of 6 weekly sessions
2. Holding on – made up of 4 weekly sessions
3. Letting go – a single session

Topics covered include: Understanding dementia, Day Services, Assessments and entitlements, Legal matters, Meditation techniques and reflexology, Nutrition, Managing change and loss, Choosing a care home, Carer’s well being.

The course is run by 2 trained facilitators with guest speakers and professionals from other agencies attending sessions as appropriate. The facilitators are able to support course attendees through the range of emotions that some of the subjects invoke. For example the first session requires attendees to consider the personal hygiene and well being needs of a person with dementia. It also provides an insight into what it is like to suffer from dementia. Other sessions discuss ways to deal with repetitive questioning, wandering etc with time set aside to discuss concerns and anxieties. These sessions are set along side more practical sessions about the range of services available locally, legal issues and benefits advice.

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The second part of the course moves on to deal with issues such as what to consider when choosing a care home, grief, loss and change, managing difficult behaviour, moving and handling, carer wellbeing and nutrition. It is aimed at people who are caring for someone with dementia in the mid stage.

The final part of the course is aimed at carer’s whose cared for have moved into residential care in the last 12 months. The main element is to enable the carer to acknowledge the journey they have travelled, recognise the milestones and share their experiences.

In Peterborough and surrounding areas, support for carers is provided by:

- Alzheimer’s Society Carer’s Support groups
- Support through community teams and day hospitals
- A carer’s centre – under the umbrella of the Princess Roayl Trust for Carers, based at Peterborough Council for the Voluntary Sector
- Service Development Officer (Greater Peterborough Primary Care Partnership)

Norfolk

The Norfolk Carer's Partnership which is made up of representative from statutory and voluntary agencies as well as carers themselves, has been working since 1999 to develop a carer's strategy for Norfolk. The current Action Plan which emerged from this strategy is for 2005-2008 and details a range of targets and partners on the delivery of services for carers in Norfolk (see case study).

CASE STUDY: Norfolk Carer's Action Plan 2005-2008

Norfolk Carer's Action Plan 2005-2008 was produced in January 2005 by the Norfolk Carers Partnership, made up of Norfolk County Council, Norfolk Health, Carers, Voluntary Agencies and the Department of Work and Pensions (see case study). It details action points and targets for a variety of agencies in the following areas:

- Strategic planning for carers in Norfolk
- Involving carers in service improvement and development
- Providing information, support and listening that carers can access directly
- Learning opportunities for carers and social services/health staff
- Improving carer's assessments and reviews: numbers assessed, their experience of assessment and the help they receive
- Providing breaks for carers
- Supporting carers health and wellbeing
- Increasing access to benefits and other funding sources for carers
- Supporting carers in volunteering and employment
- Influencing the national carer's agenda

The West Norfolk Carer's Project provide information, support and sign posting to individual carers and groups. They will provide assistance, guidance and access to grant funding to those interested in setting up a carer's support group (see case study).

CASE STUDY: West Norfolk Carer's Project

The West Norfolk Carer's Project was set up by Norfolk Social Services and West Norfolk Primary Care Trust working in partnership. They are involved in supporting carers in West Norfolk in various ways:

- Providing assistance to those wishing to set up a carer's support group. They can provide access to Social Services grants (currently £500 for setting up a group and £250 per year thereafter) as well as providing support and guidance regarding the practicalities of setting up a group
- In Kings Lynn, they organise activities for carers including meditation, Qi Gong, Tai Chi and "Stressbuster" alternative therapy sessions
- They are involved in representing the views of carers at a local and county level

Carers' information packs which contain key information are available from all GP surgeries in Norfolk and Social Services fund a Crossroads carer's helpline for carers who need support, advice or practical assistance. It operates 24 hours a day (Norfolk County Council, 2004, The Norfolk Older People's Strategy - Living Longer, Living Well).

Respite Services

Suffolk

Crossroads provides a service for carers by providing trained sitters to allow carers regular short respite breaks. Other provision is through a limited number of beds in independent and in-house establishments. Additional respite provision is currently being developed specifically for younger people with dementia at a very sheltered housing scheme at Stowupland.

Cambridgeshire and Peterborough

Six residential homes in Cambridgeshire have extra care units for people with dementia and Social Services has access to a couple of beds in each home.

One unit offers day care on 6 days per week and has 6 respite beds attached to it which are available for 5 nights per week. This allows it to offer a flexible respite service whereby people can come in for day care and an overnight stay.

Crossroads provides a service for carers by providing trained sitters to allow carers regular short respite breaks.

In Peterborough respite services are provided by the Greater Peterborough Primary Care Partnership or the independent sector.

Norfolk

"Living Longer, Living Well" reports considerable variation in provision of respite services across the county. Norfolk has 2 dedicated short-stay homes which are managed by Age Concern. (Norfolk County Council, 2004, The Norfolk Older People's Strategy - Living Longer, Living Well).

Crossroads can provide sitters or carers in people's own homes to allow carers to take a short break from caring. "Short breaks at Short Notice" is a free service that provides replacement care of this type at a few days notice – it is usually provided by Crossroads (Norfolk County Council, 2004, The Norfolk Older People's Strategy - Living Longer, Living Well).

Day Services

Suffolk

Suffolk Mental Health Partnership NHS Trust operates several day hospital services across the east of Suffolk including one at Saxmundham, several

in mid Suffolk, one in Kesgrave and one in Ipswich. They are starting to move away from providing traditional in-patient day care towards developing more outreach work and therapy for people in their own homes (Interviewee, Suffolk Statutory Services).

Age Concern Suffolk provide a day care service called "Home from Home" (see case study) which operates mainly in the Waveney area.

Suffolk Mental Health Partnership Trust provides a day hospital service in the west of Suffolk. The intention is that at the end of 2005 this will transfer out to a new build that Age Concern are undertaking in Bury St. Edmunds, called the Oasis Centre (see case study). There is also a service in Haverhill called the Tiffany unit which is jointly run between Suffolk Mental Health Services and social care. It is a specialist dementia care service available for 3 or 4 days a week depending on need.

A drop-in facility for people with dementia and their carers is being considered at Glastonbury Court in Bury St Edmunds.

Other traditional generic social services funded day services are provided from a range of residential homes across the county.

CASE STUDY: Age Concern Suffolk – Day Services

North-east Suffolk – “Home from Home”

Currently in its 4th year, this service offers the opportunity for people with dementia to become “guests” in “host carer’s” own home which is frequently located in the same community as the person with dementia. It was originally designed in response to the fact that many people with dementia find traditional day care difficult to engage with and that in rural areas, people often have to travel long distances to find a suitable service. Age concern pays and trains the host and an assistant and ensures that the house meets the required standards to run the service. Each host has 3 or 4 “guests” who are able to benefit from a range of typical day service activities in the non-institutional, relaxed and familiar environment of a private home. The service is funded by social services and the Carer’s Grant and has an open referral process with the majority of referrals coming from the Age Concern ACCESS teams.

Links Day Care Service

A specialist day care service for people with dementia run in partnership with the Community Mental Health Teams and social Services to support people with dementia.

It is run from the Wedgewood Unit of the West Suffolk Hospital and is offers 12 places per day on 2 days a week. It has been open for 2 years and offers activities within a “tranquil environment and a calm approach to care” (Age Concern Annual Report 2003-2004)

Halesworth and Reydon – Dementia Day Care Services

Both of these services offer 8 places a day for people with dementia. A high level of one to one attention is offered and a wide range of activities including live music, armchair exercises, word games, hand massage, manicure, discussion groups, arts, crafts and games.

Sudbury – Chilton day Care Centre

This is a relatively new centre which offers 12 places for people with dementia on 3 days per week.

Proposed: Active Aging Centre – Bury St Edmunds

Age Concern Suffolk are in the process of developing this centre which will provide a drop-in service and range of activities and services for older people. It is a purpose built centre which will also house 2 separate day care facilities including one for people with dementia.

Cambridgeshire and Peterborough

At the time of writing, Cambridgeshire Social Services were carrying out a review of day care provision. Cambridgeshire Social Services have access to day care places within 12 (now) independently run residential homes. Day care is also block purchased/commissioned in day centres run by voluntary and independent organisations. These are mainly in the rural areas. Some are run by large agencies such as Age Concern and Methodist Homes (see case study) but many are managed by a voluntary management committee working on its own.

CASE STUDY: Methodist Homes, Day Care Scheme, East Cambridgeshire

The Methodist Homes have been operating as a charity for approximately 60 years. They have traditionally provided residential care and sheltered housing but more recently have begun to develop extra care and very sheltered housing schemes along with more specialist day care services to meet the needs of particular client groups.

Within these client groups, the service aims to meet the needs of the individual so that rather than providing for example a range of group activities, the service would carry out individual assessments looking at social, activity and spiritual needs and then try to meet them.

They have recently opened a new day service in Wisbech called the Rosebank Centre. It is a dementia specific service, attached to an extra care sheltered housing scheme. The clients however are drawn from the local community. The range of activities provided includes: activities that maintain daily living skills, conversation, reminiscence, movement to music as well as a range of therapies including massage and the use of a sensory garden.

The centre has links with the Mental Health team and rooms are provided for specialists to work with individuals on a 1:1 basis.

The centre is currently open from 8am – 6pm and transport is provided. Clients are also able to use the centre on a “drop-in” basis for a minimum of 4 hours at a time.

Many of the CPNs from the specialist teams run “pub lunch groups” where users and carers can come together for mutual support in a social environment. There are also a whole range of lunch clubs and smaller groups across the county, many of whom are managed independently and supported by Social Services funding.

Apart from the day hospitals which provide a time limited service, there is very little specialist day care in Cambridgeshire for people with dementia. The Rural Day Care Scheme has operated in South Cambridgeshire for approximately 10 years and is now managed by the Cambridgeshire and Peterborough Mental Health Partnership NHS Trust. Run by CPNs, team assistants and an occupational therapist, the team visits 5 different villages through the week and operates from community venues such as village halls. The service is specifically for older people with mental health problems and gives places to people with both functional and organic mental health issues though mainly has people with functional mental health issues using the service (See case study).

CASE STUDY: Rural Day Care Service

The Rural Day Care Service is a day care scheme that specifically targets older people with mental health needs living in rural areas. It aims to provide a service for the scattered population of South Cambridgeshire and has been running for over 10 years. It is currently managed by Cambridgeshire and Peterborough Mental Health Partnership NHS Trust.

The scheme is based in Melbourn and delivers services to 5 different villages each week (Monday-Saturday). In each village, the scheme uses a local community venue, for example, a village hall, residential home or community centre, from which to operate. The staffing team is made up of CPN, OTs and team assistants who deliver a programme of therapeutic activities to the clients.

There is a "Health for Life" group, again in South Cambridgeshire, at Fulbourn for the functionally ill and people in the early stages of dementia. This group attends college and takes part in various activities.

Though based in Cambridge so not as accessible to people living in rural areas, "Friends of Fulbourn", a voluntary organisation, run an innovative lunch club called the "Forum Lunch Club" which is based on the model of a professional club. This group meets once a month and is aimed at people from a professional background who have developed dementia. A hot lunch is provided for both users and carers and a speaker is arranged each month. The group is well attended by people with early onset dementia.

In Peterborough and surrounding areas, Day Services are provided by Greater Peterborough Primary Care Partnership, the independent sector and voluntary agencies. Day Hospital Services are provided at Edith Cavell Hospital and Grebe House.

Greater Peterborough Primary Care Partnership has recently received Department of Health Funding to pilot a new scheme called "Home from Home". The scheme will recruit and manage trained volunteers who would open up their homes for family based day support. This service will not initially be available for dementia sufferers and will operate only in urban areas (one of the target groups is people from ethnic minority communities). However, it is hoped that the service may be able to expand in the future to operate in the rural areas surrounding Peterborough and to offer the service to people with dementia.

Norfolk

Day services are currently provided by Social services, the NHS, independent providers and the voluntary sector to varying degrees across the county. There is a debate in Norfolk as to the suitability of traditional day care services which provide care in a group setting with little

opportunity for personalised attention. There is a drive towards the development of more person centred activity (Norfolk County Council, 2004, The Norfolk Older People's Strategy - Living Longer, Living Well).

It is widely reported anecdotally by service providers that people with mild dementias frequently attend non-specialist day services until such time as their illness makes this more difficult. Specialist services exist for people with dementia, for example, Age Concern manages day centres in Methwold and Burnham Market which have designated days for people with dementia (see case study).

CASE STUDY: Age Concern, Norfolk – Methwold Day Centre

Methwold is a village located between Downham Market and Thetford. Methwold Day Centre is run from Methwold Social Club by Age Concern Norfolk. Several agencies are involved in providing the service offered. The venue is rented and paid for by Norfolk Social Services who also pay for places at the centre on a means tested basis. The centre offers day services to older people throughout the week and on 1 day per week it offers 10 places to service users with dementia. The centre also runs a mobile meals service which is managed by Age Concern Norfolk as well with meals being prepared on the premises. Manorcourt Care Ltd (an independent provider of residential and domiciliary care services) is contracted to deliver the meals to individual's homes.

A variety of activities are provided for people with dementia including crafts, card games, bingo etc during morning and afternoon sessions broken by lunch. More recently reminiscence activities have been offered both by centre staff and by outside facilitators from Norfolk County Council ,Adult Education at Wensum Lodge in Norwich. Staff also offer music sessions where percussion instruments are used by service users to accompany staff members singing and guitar playing. Tea and coffee are also served and weather permitting walks are arranged around the village. The sessions are staffed by 2 care staff and 1 coordinator. The centre employs 2 coordinators, one of whom is responsible for day care and the line management of care staff. The other coordinator manages the mobile meals service and line manages the kitchen and domestic staff. A centre manager works on 1 day per week.

The staff at Methwold are keen to develop their skills and services for people with dementia. They currently undertake individual plans for all service users and on the recommendation of an evaluation carried out by a Social Work MSc student in 2004, they have begun to focus further on providing a person-centred approach. Reminiscence work and knowledge of the individual client is an important part of this. Age Concern Norfolk is currently developing techniques for involving service users with dementia in service planning and evaluation. It hopes to roll this work out to its day centres at Methwold and Downham Market over the next few years.

Pabulum provides various types of workshops and one to one sessions for people with dementia and their carers (see case study).

CASE STUDY: Pabulum

Pabulum means “nourishment of the mind”. The organisation was set up in '98 by Alzheimer's Society and Age Concern Norfolk, supported by Norfolk Deaf Association as well as other local organisations. It provides the following services to people with dementia and their carers in Norfolk:

Reminiscence: Pairs of volunteers visit people in their own homes, supporting the person with dementia and their carer through the early stages following diagnosis. They focus on reminiscence work and often help to produce “life story books” with the person with dementia and their carer.

Remembering Yesterday, Caring Today: these are support groups for couples (person with dementia and their carer) to meet on a regular basis for mutual support and activities.

There are plans detailed in “Living Longer, Living Well” to develop specialist “Dementia Centres” which will provide individualised day care services for this client group.

Services for younger people with dementia

Suffolk

Age Concern manages an ACCESS team for people with early onset dementia which operates from Stowmarket but covers the whole of the county (see case study). This is a multidisciplinary team which provides case management services to sufferers and their carers, offers on going advice and support as well as access to services such as the Alzheimer's Society's S.P.A.C.E Project (see case study) and regular carers groups.

CASE STUDY: Lowestoft and Waveney Alzheimer's Society – The S.P.A.C.E Project

The Lowestoft and Waveney branch of the Alzheimer's Society manages the S.P.A.C.E Project which provides one to one support to people with dementia to pursue personal hobbies and interests particularly in the early stages of the disease.

It has approximately 20 open cases and employs 2 part time workers. Input was originally envisaged for 6-8 weeks with the person then moving on to pursue the interests they had developed by themselves or with support from local community groups. However, in practise experience
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has shown that it can often take longer than this to build a rapport and explore interests and that people often benefit from a longer period of support and encouragement.

The service can be used by the person with dementia on their own or together with their carer. Sometimes an outreach worker from the Alzheimer's Society branch will go along to the session to provide support for the carer separately.

S.P.A.C.E project workers spend time with the person with dementia talking and using a range of pictures and activities to stimulate an old or new interest which can then be pursued through regular sessions every 1 or 2 weeks. The first visit where interests are identified is usually followed fairly quickly with a second visit to begin to pursue the interest while it remains fresh in the mind of the person with dementia. The service is personal and individualised working at the pace of the client with the length of time and input very variable from person to person.

The service receives referrals from the Alzheimer's branch, self referral and statutory services.

No other specialist services exist for people with early onset dementia who are provided for either by working age mental health services or older people's services depending on assessment.

Cambridgeshire and Peterborough

Cambridgeshire and Peterborough Mental Health Partnership converted one of their G-Grade CPN posts to work particularly with people with early onset dementia. This nurse covers Cambridge City, South Cambridgeshire and East Cambridgeshire. Social Services has recently provided funding for 2 support workers to work with this client group looking particularly at carer and family issues. Between them they cover the whole of Cambridgeshire excluding Peterborough.

Peterborough City Council has recently been involved in looking at services for this client group and is looking to replicate the work that has been carried out in the rest of Cambridgeshire (Interviewee Cambridgeshire Statutory Services).

The local Alzheimer's Society in Peterborough runs a scheme called "Pals", the main aim of which is to enable people of all ages who are still physically fit (but who experience some degree of mental disability due to dementia) to continue to enjoy leisure activities with the support of a care worker/pal. In addition to the lunch club mentioned previously that is well attended by younger people with dementia, "Friends of Fulbourn" also run an arts project specifically for this group, with activities such as gardening and pottery.

Alzheimer's Society branches across Cambridgeshire receive regular referrals from statutory services of people with early onset dementia.

Norfolk

People with early onset dementias are admitted to either working age or older people's services depending on their assessment. They can also be transferred to older people's services as their condition progresses in order to utilise the specialist knowledge of older people's services in the field of dementia care (Interviewee, Norfolk Statutory Services).

The Norfolk and Waveney Mental Health Partnership Trust manage a specialist early onset dementia team which has been in existence for nearly 3 years. It is composed of 2 CPNs and 2 support workers who between them cover the central belt of Norfolk (See case study).

CASE STUDY: Norfolk and Waveney Mental Health Trust – Younger People with Dementia Team

This team seeks to address the needs of people with dementia who are under the age of 65. The team provides specialist workers to carry out and in-depth assessment of need that includes both medical and social care aspects and a risk assessment. This is generally carried out in the persons home and also takes into account carers needs though carers have access to an independent assessment through Social Services. This is then written up and another visit scheduled in order to go through and check that the care plan is truly representative of the person's needs and circumstances. Referrals are then made as necessary to other agencies.

For many people, the team finds that isolation is a key issue and so endeavour to build up a supportive and trusting relationship with clients that can be relied on, on an ongoing basis. The 2 support workers in the team can provide ongoing 1:1 support where people are becoming isolated. In addition, in order to address the extreme social isolation that many people with early onset dementia experience from their peers, the team works in partnership with other agencies such as the Alzheimer's Society as well as providing social support themselves in the form of social occasions, pub groups, support groups and 1:1 support.

The team is creative in its use of local resources and agencies and has linked clients in with a variety of non-specialist services. For example, "Meridian East" which is a support service for people who have been out of work for long periods of time were able to organise a computer course for one client.

Referrals usually come from neurology, psychiatry and on occasion from social work. Referrals from the team to social work currently have to go through "Customer First".

Other

Regional

Dementia Focus is a group that meets each quarter at the University of East Anglia. It is made up of representatives drawn from the statutory, voluntary and independent sectors of Norfolk, Cambridgeshire and Suffolk as well as representatives from the Universities. The group aims to further research and development of dementia services in the eastern region and to build links between agencies.

Dementia Focus secured funding in 2005 from Norfolk, Suffolk and Cambridgeshire Workforce Development Confederation to provide a basic Dementia Care Mapping Training Course for staff in the Eastern Region Strategic Health Authority (see case study).

CASE STUDY: Dementia Care Mapping

Dementia Care Mapping (DCM) was originally developed by Professor Tom Kitwood, based at Bradford University. It is a tried and trusted tool which can improve the quality of care for people with dementia when used as part of a Quality Assured or Practice Development Framework. Supplementing standard approaches, which focus mainly on the care structure, it provides a systematic method to look in detail at the care process and its effect on well being.

By assessing care from the point of view of the person with dementia, DCM goes to the heart of caring for someone with dementia. It involves making detailed observations and recordings of the interactions experienced by people with dementia in formal care settings. The result is a dementia care 'map' for an individual person with dementia, from which data can be analysed and immediate feedback can be given to the direct care staff with the aim of improving practise. It can be used to help pinpoint positive areas in the care process as well as those which require change and also to measure improvements in care over time.

Training in DCM is only available from Bradford Dementia Group licensed trainers, who have themselves undergone rigorous training. The training is accredited and attendees will receive a University of Bradford certificate. It was offered to 90 members of staff drawn from the 3 Mental Health Care Trusts, the three Social Services Departments and PCTS in Norfolk, Suffolk and Cambridgeshire and staff from the independent and voluntary sector who are involved with residential care or ward focused care of people with dementia. The basic DCM course qualified those who passed the assessment to use DCM in any dementia care setting.

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DCM is most effective when it is used as part of an ongoing cycle of evaluation. It is expected that following training, staff will undertake 'baseline mapping exercises' with individual residents. They will then be able to feedback to team members and put together an action plan for improvement in readiness for a second map to be carried out within 6 months. It is anticipated that this process of evaluation will improve the level of care to residents – by virtue of a better understanding of their needs, of their interactions with others and of communications by others with them. An evaluation report of the training is available from Dementia Focus (School of Social Work, UEA).

Across the region, voluntary organisations provide a number of services and support to people with dementia and their carers. These services are often non-specialist and supported by a small voluntary management committee and minimal funding. Larger voluntary agencies such as Age Concern, WRVS, Alzheimer's Society and Crossroads have carried out work with local volunteers and communities to improve capacity and ensure that information is as accessible as possible in the more remote areas.

Suffolk

The drafting of Suffolk's Older People's Mental Health Strategy demonstrated the difficulties of mapping which Older People's Mental Health services are available and where. The strategy recommends a "robust mapping process" (p24, Draft 9, 17.01.05) to be carried out in order to provide base line data of what is available. Suffolk Mental Health Partnership NHS Trust is part of a mapping exercise in conjunction with Durham University which will produce this information along with a directory for users and carers and qualitative feedback on services.

Non-statutory agencies provide a range of support and information to people with dementia and their carers and use often innovatory means to ensure that information is widely accessible, for example Age Concern's "Local Links" (see case study).

CASE STUDY: Age Concern Suffolk – Local Links

In order to publicise and provide services to as wide an area as possible and to inhabitants of very rural areas, Age Concern Suffolk operate a system of "local links". These are volunteers who are in touch with their local community and can act as a contact and information point for older people in their own community. It is believed that these individuals are more "in touch" with the needs of older people living in their community and can assist with early identification of possible issues affecting older people. Funding from the East of England Development Agency enabled Age Concern to recruit a co-ordinator to expand the number of volunteers involved and to promote this service. It is hoped that this system of local link volunteers will help to break down the social isolation experienced by many older people living in rural and urban communities.

Age Concern Suffolk covers the whole of the county providing assistance with benefits claims, managing finances, social support, advice as well as more specialist services such as those provided in day centres and through community ACCESS teams described earlier. The Alzheimer's Society has branches across the county, many of whom have outreach workers who provide ongoing support, advice and information in a group setting and on a 1:1 basis.

A voluntary agency called PASS can provide support and assistance in accessing direct payments for services.

Cambridgeshire and Peterborough

There is one branch of Age Concern in Cambridgeshire covering the whole of the county. It provides some generic services for older people: 5 day centres, drop in café (Cambridge City), Information service, Volunteer Visiting Scheme, Home help and Community Wardens (charged for). Figures for numbers of people accessing these services who suffer from dementia are not available. They also run a Mental Health Advocacy Service (see case study).

Mental Health Advocacy Service, Cambridgeshire

Age Concern Cambridgeshire's Mental Health Advocacy Service now covers all areas of Cambridgeshire apart from Peterborough. It is funded by Social Services and the Primary Care Trusts. It employs 1 fulltime team leader, an administrator and 3 part time advocates. A number of volunteers are also involved. The steering group is made up of representatives from Age Concern, the Alzheimer's Society, NHS and Social Care agencies.

It is an independent service that was set up to provide a way for people *"...to express their needs and have a voice and get their problems sorted"* (Senior Manager, Age Concern Cambridgeshire). The majority of referrals come through Statutory Services though people are also able to self refer.

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Key issues encountered by the service are people being unable to manage their finances without support and people needing support to adapt their current living arrangements or to identify suitable alternative accommodation (Senior Manager, Age Concern Cambridgeshire).

The service currently has over 80 cases of varying degrees of complexity and recently had to start a waiting list. The service endeavours to be time limited though the crossover into a befriending service is sometimes difficult to avoid. The team has 1 or 2 cases where they offer ongoing low-level maintenance which is generally for financial matters for example: people who have no one to collect their pension for them (Senior Manager, Age Concern Cambridgeshire).

Generally, following referral, there is an initial visit or series of visits to build a relationship with the client and carry out an assessment. After this, often, much of the support provided is by telephone. Cases often involve the advocate making a number of calls on behalf of the client to other agencies. In many cases the work can be extremely intensive with workers spending a great deal of time with one person or one family in order to resolve the issue that has arisen.

Travel costs and journey times, like all services in rural areas, are high and the team is organised so that workers cover specific areas in order to limit this as much as possible.

In addition to the services described earlier in this report, the Alzheimer's Society has branches across the county, many of whom have outreach workers who provide ongoing support, advice and information in a group setting and on a 1:1 basis.

Norfolk

Direct Access Services are available from Norfolk County Council which do not require older people to be assessed for eligibility. They currently include: luncheon clubs, bathing, Crossroads, befriending, exercise classes, reminiscence, IT training, carers training, mobile meals and Home Call.

Independent Living Norfolk (ILN) supports people to access direct payments in order that they can purchase services that will support them to live at home. ILN will assist with recruitment and payroll and provide employment advice, acting where appropriate as the person's agent in the recruitment and administration of care provision (Norfolk County Council, 2004, p67).

"Living longer, Living Well" proposes the development of Community Support Centres for Older People which would offer a range of services

including information, advice and signposting, day services and residential beds. A number of models for these centres are being considered.

There are branches of Age Concern and Alzheimer's Society in various locations across the county. They carry out a similar range of activities to branches in Norfolk and Suffolk involving support, information and advice on a 1:1 and in group settings as well as the day centres and activities described earlier in this report. Age Concern Norfolk is involved in research and development work across the county (see case study) and is represented on several county wide working parties and strategy groups.

Age Concern Norfolk – Research and Practise

Age Concern's Norfolk Branch employs a Research Manager to co-ordinate and manage research relating to older people. A range of studies have been carried out which focus on the collection of views of older people themselves. For example, a study (Maintaining and Developing Social Networks and Activities: Older People Living in Long Term Residential Care and Housing with Care Schemes) was commissioned by Norfolk's Older People's Strategy Project Group as part of its consultation for the strategy "Living Longer, Living Well".

In January 2003, "Involving Older People in Service Planning, Older people designing quality standards and initiatives for day centre services" was published. This study was funded by Averil Osborn Trust and supported by the British Society of Gerontology. It was one of the 4 short listed projects in the Older People and Intermediate Care category of the 2002 Community Care awards, judged to be offering "highly innovative and empowering services of high standard".

Over an 18 month period, the study supported service users to design quality standards for Age Concern, Norfolk's day services as well as methods of evaluating these criteria against the experiences of service users. The project also sought to gain insight into the types of contributions older people might be willing to make in service planning and evaluation.

Age Concern Norfolk is keen to pursue this type of work with people with dementia who were not included in the study outlined above. They are currently developing a service at Diss in Suffolk which will provide day care for people with dementia on 2 days per week as well as support for carers. This would be part of a broader resource centre which would be available to all older people living in the local community.

They are extremely keen to engage service users, including those with dementia and their carers at the point of decision making to be involved in designing and evaluating this new service. They hope following on from a pilot of this type of innovatory work at Diss, they would then be able to roll it out to include service users with dementia using other Age Concern services across the county.

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