

**JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE AND COMMUNITY
AND OLDER PEOPLE POLICY AND SCRUTINY COMMITTEE TASK AND FINISH
GROUP**

SCRUTINY REPORT ON DEMENTIA SERVICES IN ESSEX

MAY 2011

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DEMENTIA SERVICES IN ESSEX

Foreword by Councillor John Baugh, the Chairman of the Task and Finish Group

From the outset it was clear that this study would be complex and diverse. The extent of problems regarding future dementia services is easily understood. Those born in the post-war 'baby boom' are living longer and approaching ages when they will be most at risk of dementia. Other factors may contribute to the projected growth in numbers of people with dementia. The mission of the group was to unravel the many factors at work in delivery of services and the experience of carer and patient with dementia to produce a coherent set of suggestions which might improve dementia services in Essex.

Hitherto carers provided daily management of their situation without adequate resources and support, with this continuing for many years until they were unable to cope emotionally and physically. Self funding carers fared worst. Carers themselves have spoken of lack of information and poorly co-ordinated services. Final outcomes – usually 2 years in a residential care home – took the majority share of direct costs of dementia care with only 11% of total costs pertaining to domiciliary help, aids/adaptations and day care. With current UK social costs of dementia assessed at £23 million per annum and projections showing dementia cases doubling within the next 30 years, the traditional model cannot continue in this climate. It is financially unsustainable, inhumane and deeply flawed in its logic.

The Group sought to build on recent improvements, for example the Crystal Centre adjacent to Broomfield Hospital, the Joint Commissioning Board and Personal Care Budgets. We sought a direction which offered comprehensive co-ordinated services of higher quality within a climate of funding limitation – to address the physical and psychological needs of carers and cared for. It is for others to cost the delivery of services and to design a suitably adaptable delivery system but some initiatives we examined appeared to offer good cost effective outcomes. It was a particular pleasure to discover the variety of services and depth of involvement contributed by the voluntary sector, adding quality to overall provision. My greatest privilege was to meet those living with dementia, both carers and cared for, and the wonderful volunteers who helped enrich their lives.

Approaches to any matter of ill health have three elements: prevention, management and cure. In the early stages of the group's investigations only the middle option seemed available with regard to dementia. At the time of writing we are encouraged by the (unverified) suggestion in the media of a pharmacological solution to halt progression of the disease. Even more hopeful is the possibility of long term prevention through picking up signs of pre-dementia conditions and putting preventive programmes in place to dramatically delay onset of the disease. In the immediate future, better management and more diverse interventions could offer an improved quality of life for the person with dementia and the people caring for them.

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Background

In 2010, the Essex Health Overview and Scrutiny Committee (HOSC) arranged an away day event with colleagues from the Southend and Thurrock HOSCs, the Essex and Southend LINK and all five Primary Care Trusts serving parts of the county (Mid Essex, North East Essex, South East Essex, South West Essex and West Essex). This gave an opportunity for the HOSC to look at the strategic issues affecting the county at the time and at those issues which would be of major significance over coming years.

It became clear that an issue of concern to all parties was how to deal with the increasing number of people with dementia. The HOSC decided that this subject should be included as one of the major items on its Forward Look for 2010/11. Whilst this is an issue of major national and international significance, the HOSC agreed that it should concentrate on how the issue might be dealt with locally.

The scrutiny process

The HOSC agreed that it would not be appropriate for it to look at this subject in isolation from other agencies. It wished to involve other appropriate parties to serve alongside HOSC representatives on a Task and Finish Group. Invitations were offered to, and accepted by, the Essex County Council (ECC) Community Wellbeing and Older People Policy and Scrutiny Committee (CWOP) and the two Partnership NHS Foundation Trusts providing mental health services in the county.

The final membership comprised:-

HOSC - County Councillor John Baugh (Chairman) and District Councillor Malcolm Maddocks

CWOP – County Councillors Sandra Hillier and Janet Whitehouse

Partnership Trusts – Mr Ray Cox and Mr Steve Currell

The Group was supported by Graham Redgwell and Graham Hughes from ECC's Governance Team.

The objectives of the scrutiny were agreed as:-

- (1) Discuss issues around the level of dementia in Essex.
- (2) Look at examples of good practice, both locally and nationally.
- (3) Discuss options for the way forward.
- (4) Suggest proposals to appropriate parties for a viable approach to future care and treatment.

These were chosen initially to give as wide a scope as possible. The Group remained very satisfied with these as objectives and made no changes during the course of its scrutiny. It was also clear to the Group that any proposals coming from the scrutiny would need to be evidence-based and form a coherent and strategic way forward.

It was agreed that the scrutiny would gather evidence from four sources:

- Written publications in the public domain.
- Written contributions from witnesses.
- Witness sessions.
- Member visits (undertaken by either the Group as a whole or by Members as individuals).

During the course of the scrutiny a number of acronyms and technical terms came up. These are detailed in the glossary attached as annex A to this Report. Some useful diagrams and graphs presented by witnesses are reproduced in this Report with those persons consent. Contact details for Thinking Fit and the Essex Reminiscence Network are set out in Annex B.

Written evidence

This was obtained from a number of sources (academic papers: National Government publications; publications by other national Governments and outside agencies; National Health Service publications; Essex County Council publications; a conference attended by the Chairman; third sector publications; professional journals; and reports by Members on individual visits). Copies of each document referred to in this Report are held on file and retained by the Secretary of the Essex HOSC for reference purposes. This enabled a very extensive library of supporting material to be obtained.

The documents seen by the Task and Finish Group (in order) are:

- Components of total cost of dementia care (Royal College of Psychiatrists)
- Living with Dementia – A National Dementia Strategy (DoH)
- A Rights-based approach to a Dementia Strategy (Mental Welfare Commission for Scotland)
- Ethical issues - the needs of carers (Nuffield Council on Bioethics)
- Protecting the rights of people with dementia (Mental Welfare Commission for Scotland)
- Implementing the National Dementia Strategy in London (NHS Commissioning Support for London)
- What are the levers to improve quality and value for money for dementia services in England? (National Audit Office)
- The effectiveness of local health and social care services (Essex and Southend LINK)
- Mental Health Services for Older People in North Essex (North Essex Partnership NHS Foundation Trust (NEPFT))
- Consultation document on provision of services in Lucas Ward, Colchester (NHS Mid Essex)
- The Crystal Centre, our service (NEPFT)
- An individuals' experience of residential care ('Mrs X')
- Notes of meetings of Alzheimer's Society Carers Discussion Groups (Chairman)
- National Dementia Declaration for England (Dementia Action Alliance)
- Thinking Fit Programme (Essex County Council)

- Funding arrangements for Alzheimer's Society Public Information Officer (Essex County Council)
- Funding support for voluntary organisations (Essex County Council)
- Services provided by Alzheimer's Society in Epping Forest district (Essex County Council)
- Services provided by Alzheimer's Society and its views on a way forward (Locality Manager, Alzheimers Society)
- Connecting Carers - Winter 2010 edition (ECC)
- Quality outcomes for people with dementia - Building on the work of the national dementia strategy (DoH)
- Drug use appraisal consultation document (NICE)
- Various magazines and booklets for public use (Alzheimer's Society)
- Dementia Services Action Plan and Older Adult Mental Health Strategy (ECC)
- Protocol for the Thinking Fit project (University College London and NEPFT)
- Essex Reminiscence Network (ERO)
- Recollection and the UK Museum: Object, Image and Word (University of Leicester)
- The effects of reminiscence on depressive symptoms and mood status of older institutionalised adults in Taiwan (Fooyin University)
- Reminiscence therapy with older adults (E O'Leary and N Barry)
- Effect of reminiscence therapy on depression in older adults: a systematic review (Fooyin University)
- The effect of reminiscence on the elderly population: a systematic review (Fooyin University)
- Reminiscence therapy for dementia (The Cochrane Collaboration)
- Disabled Parking Badge scheme for parking concessions for disabled and blind people (ECC)
- Alzheimer's Society funding (Alzheimer's Society)
- Views on dementia services (Epping Forest PBC Consortium)
- Views on dementia services (Ranworth Surgery, Clacton-on-Sea)
- Dementia Action Alliance and National Dementia Declaration for England (DAA)
- Case studies (Alzheimers Society and ECC)
- Support, Stay, Save (Alzheimer's Society)
- Services provided by Alzheimer's Society in West Essex (Alzheimer's Society)
- Dementia 2010: the economic burden of dementia and associated research funding in the United Kingdom (Alzheimers Research Trust)
- World Alzheimer Report 2010: the global economic impact of dementia (Alzheimers Disease International)
- Preventing Alzheimers disease and cognitive decline (US Department of Health and Human Sciences)
- Advice to General Practices (Essex Local Medical Committee)
- Thinking Fit progress report (NEPFT)
- Lesson Plan: reminiscing with older people (ERO)
- 'Still Part of the Community' (Housing 21)

The Secretary of the Essex HOSC also liaised with colleagues dealing with other HOSCs in the east of England region and invited them to pass on details of any scrutiny work on dementia services that they had carried out.

Oral evidence

The Group held a number of witness sessions. All but one of these was held in public. Due to its nature, the visit to the Crystal Centre (and the ensuing discussions with staff) was a private event. Oral contributions were made as follows (the post title shown is that held at the time of the interview):

- Sally Morris, Executive Director of Operations; and Dr Charles Olojugba, Consultant Psychiatrist, South Essex Partnership University NHS Foundation Trust, to discuss dementia services within south Essex.
- Jenny Owen, ECC Deputy Chief Executive, to discuss the national strategy and joint working in Essex.
- Naushad Nojeeb, Operational Services Manager; Vickie Glass, Practice Development Lead; and Michele Thompson, Team Leader, Memory Assessment and Support Service, to discuss the role of the Crystal Centre adjacent to the Broomfield Hospital site, followed by a tour of the Centre.
- Chris Martin, Senior Manager, Strategic Commissioning; and Sheila Davis, Strategic Commissioning Officer, ECC, to discuss the Older Adult Mental Health Strategy in Essex.
- Kay Ellis, to discuss personal comments on the provision of services in West Essex and general comments on behalf of the Epping Branch of the Alzheimer's Society and the Essex and Southend LINK.
- Dr Thomas Dannhauser, Specialist Registrar in Psychiatry, and Steven Cleverley, Clinical Research Fellow, NEPFT, to discuss the research undertaken as part of the Thinking Fit project.
- Dr Mark Curteis, Heritage Learning and Access Officer, ECC Essex Record Office, to discuss the Essex Reminiscence Network and the development of memory boxes.

Group members also reported on meetings that they had held with local groups, individual carers and General Practitioners.

The national position

During the course of the scrutiny, a number of events took place nationally, which influenced the Group's thinking:-

- (1) The General Election in May 2010 brought about a change of Government.

- (2) There are substantial savings required in health and local authority budgets for the period 2011/12 to 2014/15 as the Government seeks to reduce levels of public expenditure and redirect funding to prioritised areas .
- (3) The new Government introduced proposed legislation to restructure the commissioning arrangements in the National Health Service.
- (4) A number of national agencies and charities jointly introduced the National Dementia Declaration, announcing the launch of a Dementia Action Alliance to transform the quality of life for people affected by dementia.
- (5) The National Institute for Health and Clinical Excellence (NICE) issued an appraisal document indicating that certain drugs (donepezil, galantamine, rivastigmine and memantine) should now be available at much earlier stages in a dementia patient's treatment.
- (6) The National Strategy issued by the DoH was updated in late 2010, to reflect experience in its initial period of operation and the opinions of the new Government.
- (7) The Alzheimer's Society issued a report 'Support. Stay. Save.' in January 2011, about the care and support of people with dementia in their own homes.

The Status Quo or Change?

The Group's first and fundamental issue to consider was 'Could the status quo continue'?

The number of people living with dementia has increased over recent years and, with people living longer, the numbers will inevitably continue to increase. With improved drug regimes and closer working arrangements between agencies, people with dementia are likely to live longer whilst having the illness. Current economic conditions dictate that the agencies involved will need to save substantial sums of money for many years to come. Given all these circumstances, the Group feels strongly that the status quo is not sustainable and that doing nothing is not a viable option. This view is reflected in the work going on nationally in looking at this subject.

Having agreed that, what can be done?

The Group made many findings during its scrutiny. These are set out below. However, it has tried to be realistic and has therefore limited the number of recommendations. There is no point in putting forward proposals which expect agencies to be able to find additional funding. Clearly agencies will not be receiving extra funding to provide additional services and any changes will have to be met from existing resources and, potentially, a virement of funds. Working together and sharing resources between agencies will clearly be vital.

Findings

During the course of the scrutiny, the phrase 'A Living Bereavement' was used. The Group felt this to be a very apt and accurate view of severe dementia.

A number of the issues discussed are still at a relatively early stage of their development. The Group has therefore often had to consider the actual progress made and compare this against projected outcomes.

Many findings were made and are grouped under a range of headings below.

Dementia in the national context

- This is a national and not just an Essex problem. There are currently about 750,000 to 850,000 people in the UK with some form of dementia, with the number expected to reach at least one million by 2025. There are also a similar number with a milder cognitive impairment. The overall public expenditure cost of assisting these people is currently of the order of £20 to £23 billion per annum. The amount of money spent on research is, however, very limited compared to that spent on other major illnesses (see attached table).
- The mental health profession recognises three levels of dementia – mild, moderate and severe.
- There is a National Dementia Strategy in place, which has been accepted by both the previous and current Governments ("the National Strategy"). It has 18 objectives (17 in original document and one added subsequently) as follows, and all Health and Social Care bodies are expected to sign up to the National Strategy. The 17 original objectives are:
 - Improving public and professional awareness and understanding of dementia.
 - Good quality early diagnosis and intervention for all.
 - Good quality information for those with diagnosed dementia and their carers.
 - Enabling easy access to care, support and advice following diagnosis.
 - Development of structured peer support and learning networks.
 - Improved community personal support services.
 - Implementing the Carers Strategy.
 - Improved quality of care for people with dementia in general hospitals.
 - Improved intermediate care for people with dementia.
 - Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers.
 - Living well with dementia in care homes
 - Improved end of life care for people with dementia.
 - An informed and effective workforce for people with dementia.
 - A joint commissioning strategy for dementia.
 - Improved assessment and regulation of both health and care services and evaluating how systems are working for people with dementia and their carers.
 - A clear picture of research evidence and needs

- Effective national and regional support for implementation of the National Strategy.
- The added Objective is:
 - Reducing the level of use of anti psychotic drugs.
- ECC has a major direct input to the preparation and implementation of the National Strategy through the involvement of Jenny Owen, who is one of the three National Champions (she is the Champion for Social Care with the other National champions being Sir Ian Carruthers (NHS) and Martin Green (independent sector).
- The four DoH policy development priority areas in 2010/11 have been:
 - Good quality early diagnosis and intervention for all.
 - Improved quality of care in general hospitals.
 - Living well with dementia in care homes.
 - Reduced use of anti psychotic medication.
- The Government has made a commitment to drive up quality and improve dementia care services. This work will be supported by the Dementia Action Alliance (DAA), with the aim by 2014 of being in a position so that people with dementia can say:
 - I have personal choice and control over the decisions about me.
 - I know that services are designed around my needs.
 - I have support that helps me live my life.
 - I have the knowledge and know-how to get what I need.
 - I live in an enabling and supportive environment.
 - I have a sense of belonging and of being a valued part of family, community and civic life.
 - I know there is research going on which delivers a better life for me now and in the future.
- It is too early at this stage to gauge the effectiveness of the DAA (i.e. its first annual report will not be published until early 2012).
- The average cost of caring for each dementia sufferer is in the region of £27,000 per annum.
- The expert medical advice available suggests that the changes put forward by NICE are welcomed. The Group does not have the expertise to comment on this.
- Dementia can occur from the mid 40's upwards but is primarily found amongst those aged 65 and above.

Medical issues

- The latest reports (April 2011) show there is in the region of 18,600 to 19,400 people with dementia in the county area of Essex – a breakdown district by district is given in the attached table.

- Dementia is often linked to a physical ailment, which needs to be treated first, often as a matter of urgency.
- Referrals for treatment for dementia are often made too late for any strong remedial measures to be taken.
- Research shows that the numbers of people with dementia in the upper age bracket (85 to 95 years) will increase dramatically in the next 10 to 15 years. That age group is likely to have extensive mental and physical needs and may not have a carer capable of looking after them at home.
- Dementia can be diagnosed and/or referred from a number of sources – self diagnosis, family referral, GP referral, referral from residential or nursing home, Clinical Assessment Team, Community Mental Health Team or it can be recognised following hospital admission for another reason.
- Mental health is split into two types of illness – organic (e.g. dementia); and functional (e.g. depression, anxiety, psychoses and bi polar disorder).
- Memory Assessment and Support Services enable early diagnostic intervention and assessment for treatment.
- Many with dementia have no or little memory of recent events but there is clear evidence that they can recall events from some decades ago. The Essex Reminiscence Network can play an important role in releasing these memories. Essex County Council is at the cutting edge of this work and is seen as the clear lead in the East of England region.
- Regular monitoring is required after initial assessment, to prevent rapid decline.
- The Crystal Centre, adjacent to Broomfield Hospital in Chelmsford, provides a specialist inpatient service and community assessment and care to people aged over 65 years who live in the Mid Essex area with mental health problems. It is an excellent facility, bringing a range of previously scattered services together, but only has capacity to cater for patients from mid Essex and is unlikely to be replicated in other areas in the current financial climate. The Crystal Centre deals with a range of cognitive impairment needs, not just dementia, and the memory assessment and support service is non-age specific. However, it is relatively new and it is too early yet to demonstrate its cost effectiveness and level of added value. Initial external evaluation by Bournemouth University is however promising.
- The Group does not have the expertise to comment on the efficacy of particular drugs or psychiatric treatments.
- There are a number of examples of good practice taking place between agencies in Essex to avoid the use of antipsychotic drugs. Two examples which the Group found of a particular use to patients and appeared to be of a high standard are:

- Managing Sundowner Syndrome.
 - The Thinking Fit trial, which encourages a combination of brain training, physical exercise and group activity.
- The Thinking Fit programme is, however, only suitable for those with a milder cognitive impairment. Initial projections show that it offers value for money, with a current cost per patient of £4,000 per annum, which includes initial set-up costs and which could fall with greater economies of scale. A number of participants have expressed a wish to continue meeting together and supporting each other, which will require obtaining premises and a degree of voluntary sector support.
 - Long term nursing/residential care and urgent hospital care takes up the major share of dementia care costs. In the presentation on Thinking Fit, the Group was advised that the figure in Essex for such formalised care is about 95% of the total spent on care in the county for dementia sufferers. Nationally the figure is less, but still in the order of 85% to 90%.

GP related issues

- It is important to involve GPs in planning services in advance of GP commissioning consortia being established. Consortia will need to consider how they will wish to commission dementia related services.
- Evidence from medical practitioners indicates that GPs appear to have no national or countywide guidance on how to deal with patients displaying symptoms of dementia or other cognitive impairments.
- There does not appear to be any continuing professional development programme for GPs in relation to cognitive impairment issues.
- GPs do not appear to have any specific processes or guidance for dealing with requests for information about dementia and have limited literature on the subject available for public use.

Essex County Council internal issues

- The Essex Dementia Services Action Plan has been rewritten recently and was out for consultation at the time this Report was prepared. The Group had been able to comment on this Plan at an early stage in its preparation.
- The Essex Dementia Services Action Plan proposes prioritising four areas of activity from the 18 national priority areas. These are:
 - early diagnosis and support
 - improving the quality of acute hospital care
 - improving care home quality
 - reducing the use of anti psychotic drugs
- A number of witnesses indicated that Community Mental Health Teams are considered to be a good model of working and encourage co-ordinated

working. In particular, these Teams have access to people living in the community and can monitor them on a regular basis.

- The Group welcomed the reasoning behind the Older Adult Mental Health Strategy, as it considers all social care, housing and non active health services under one heading. This is still at an early stage of development but should be encouraged. There will be a need to review implementation of objectives after a reasonable timescale (say summer/autumn 2012) to ensure that the anticipated progress is being achieved.
- ECC is at the forefront of promoting Personalised Budgets, which gives people more freedom to decide on their needs and how those needs will be met. It was noted that there is less use of this option amongst people with dementia.
- ECC funding to the voluntary sector in 2010/11 in respect of dementia-related services amounted to £1,128,913. There are no guarantees about the level of support that will be available in future years. From the Health perspective, PCTs also make funding available to the voluntary sector
- Essex Adult Community Learning Services (and nationally NIACE) is involved in progressive programmes assisting group work amongst persons with a cognitive impairment. Some involve professional staff from both the Health Service and the County Council but NIACE services are provided by volunteers.

Caring issues

- The word 'carer' is not particularly liked by all partners and close family members, but it is a recognised term in general use.
- A number of witnesses indicated that there are a limited number of places available in day care or respite care centres run by the voluntary sector. Those that do exist often have to share what premises are available with other voluntary bodies running other activities for different client groups. The level of demand far exceeds supply.
- The most affluent areas in the county have the most active voluntary groups.
- Carers indicate that even a limited amount of respite care of appropriate quality is important to them.
- Many people with dementia rely entirely on one carer, who is often elderly and frail themselves. There are some who have no support at all from family and friends. Often, the assessments of the person with dementia and their carer are considered separately, although they live in the same house, invariably spend most of the time with each other, and may well have similar needs.
- Carers indicate that they receive limited advice and support.

- There is limited funding available to undertake skill-based training for carers. There is very much an onus on carers to seek out support mechanisms.
- Carers mentioned how irritating and time consuming it is to be passed around between agencies, and stressed the importance of having one named contact. The use of a single contact telephone number by SEPT is seen as an example of good practice.
- There is no specific service geared to the small but existing group of younger dementia sufferers (those under 65 years of age).
- A care home is realistically seen by a carer as the end of life experience for the person with dementia. There is often a reluctance to let a family member go into residential care even though the carer feels that they cannot continue to offer adequate care themselves.

Other matters

- There is no consensus on whether people with dementia in residential care are best provided for (a) in a small unit as part of an Older Peoples Home; or (b) in a specialised dementia home.
- The Alzheimer's Society has split its national and regional campaigning activities from its local group's day care and day to day related work.
- The Alzheimer's Society publishes many helpful and useful booklets but assumes a high level of computer use to access these.

Recommendations

Towards the end of its work, the Group held two private sessions, to look at the evidence it had received and to consider its proposed recommendations. In drawing up its proposals, the Group had in mind the following points:

- Why is the recommendation being made?
- Who is it aimed at?
- Does it have any cost implications?
- What timescales are proposed?
- Does the evidence gathered support the proposal?
- How will any changes be monitored, and benefits measured?

Each proposal was measured against these points. Each was also looked at closely to confirm that it met one or more of the objectives the Group had set itself.

The Group often remarked on how much more attention was now being given to dementia. Reports were appearing in the media at regular intervals in relation to new research, innovative projects being trialled and strategies being updated. The magnitude and seriousness of the issue now seems to be well recognised. This does mean, however, that much of the work is still at an early stage. The events taking place in Essex are no exception.

The Group is convinced that much innovative work is happening but, in many cases, it is too soon to draw any conclusions or ascertain their value for money. The Group feels that giving time for appraisal is vital and **RECOMMENDS** as a fundamental principle that all the projects being trialled must run their course and then be fully self evaluated and the outcomes audited and monitored by an appropriate body. On the evidence available, the projects appear to show great potential and could lead to significant changes in the next few years. It is also important that the results of these trials are made widely known – all good practice must be shared.

The Group then looked at what actions might improve the standard of life of both the person with dementia and their carer(s) and delay the time before it is necessary to go into residential or nursing care. The Group acknowledge that, whilst there might be some initial costs, these should be limited and the proposals should ultimately be self financing. The cost of residential and nursing care far outstrips that of care in the community.

Any move towards action at an earlier stage of diagnosis will require a co-ordinated approach by all agencies. The Group is impressed that agencies in the county have grasped this and are working closely together. This was clear in the evidence presented by witnesses and the work seen by Group members. As an example, the Thinking Fit trial has been funded by the Essex County Council, with research staff from NEPFT and day-to-day support from staff from a range of agencies.

To further this aim, the Group **RECOMMENDS** that:

- There should be a continued and greater use of assistive technology (such as Telecare and aids/adaptations) to enable people to live at home as long as possible. The creation of the Essex Cares organisation seems to have cut the level of bureaucracy and sped up processes in this respect.
- There needs to be a co-ordinated approach in looking at both physical and mental health needs of the carer and the person with dementia together, rather than in isolation.
- Anyone over 65 attending a health check should receive advice on their first visit and be advised of symptoms to look for themselves and that they should be encouraged to follow a mix of brain and physical activity to delay the onset of more severe cognitive impairment (research shows a substantial delay in the onset of dementia by following a programme of such activities).

The Group was very concerned to hear on a number of occasions about the lack of advice GPs receive on how to recognise and deal with dementia. Many people with dementia will first present themselves at a local surgery. The Group noted the lack of both any specific diagnostic tools and any general guidance and **RECOMMENDS** that this issue is taken up with the Department of Health, as it clearly has implications far beyond the borders of Essex. This will be of even greater importance in the future, when GP consortia become responsible for most of the health commissioning budget. On a number of occasions, the first individual recognising a person with dementia may well be a chemist or pharmacist. Local chemists and pharmacies

could usefully be provided with more information on how to assist their customers and provided with clearer pathways of referrals to pass on to individuals and/or their carers.

The Group then looked at other ways of assisting people to continue to live in the community. It recognises the valuable support given by voluntary organisations, on often very restricted budgets. They fulfil a clear need, particularly in giving respite care, and could provide more, given appropriate budgets. Whilst funding agencies have limited resources themselves, the Group **RECOMMENDS** that they should consider requests from voluntary organisations dealing with cognitive impairment clients sympathetically. If possible, they should offer some form of security and accountability through the use of Service Level Agreements for a period of at least three years.

Carers often remarked on the irritation of having to recount their story many times to different agencies and on the amount of form filling required. The Group **RECOMMENDS** that all agencies should consider, within countywide strategies and action plans, how best to establish a 'one stop shop' for carers, where they can receive the best level of advice and support. It is felt that this could potentially be an area for the newly created Healthwatch organisation (as a public led and public focussed body) to consider and advise upon best practice.

One innovative project the Group discussed is the Essex Reminiscence Network, where the Essex Record Office has taken the leading role. It is now spreading its expertise across the East of England region. This work can be relevant at all stages of a dementia patients life and is a very valuable tool that can be taught to carers. It is, however, very dependent upon the interest and expertise of two members of staff. The Group **RECOMMENDS** that this work be encouraged, acknowledging that it may need to become self financing rather than provided free of charge, as at present. The Group also encourages the work undertaken by bodies such as NIACE and the University of the Third Age, as continuing education and learning is shown to have major medical benefits.

The Group is aware that, in some cases, a person with dementia will need to move into residential care. Realistically, for many this is seen as the 'last stage' of their life. By this point many will be presenting challenging behaviour. The Group strongly endorses the national and local priorities to reduce the level of use of anti psychotic drugs and **RECOMMENDS** that this stance is stressed by all agencies in their dealings with private homes. The Group supports and commends the use of alternatives to anti psychotic drugs and would suggest that this issue should be a major component of any inspection regime. It notes that three of the four priorities in the Essex Dementia Services Action Plan relate to this part of the overall service to people with dementia.

The Group is aware that clients placed in homes by local authorities will be visited by social workers and their cases will be monitored. However, there does appear to be a gap as far as self funding clients are concerned. Whilst such self funders may be visited by family and friends, who is responsible for reviewing and monitoring their cases? The Group has no definitive answer to that question but does wish to bring the issue into the public domain for further debate. It is clear that the responsibility

for the medical care of self funders lies with their GP. As far as social care is concerned, the Group would suggest that social workers visiting a home should have a general 'brief' to look out for the well being of any resident, although it acknowledges the difficult legal and human rights issues involved in this. There might also be a need for a formalised advocacy system to be established. This is a loophole that needs further debate.

The Group has quoted some financial costings in this report. It has tried to come forward with a strategy that uses the limited funding wisely and to the benefit of the maximum number of people possible. It **RECOMMENDS** that the financial implications of any changes need to be taken account of in the Essex Dementia Services Action Plan.

The Group commends this Report to the HOSC and CWOP. As much work is still at an early stage, it **RECOMMENDS** that the matter be monitored from time to time and than followed up in detail after 18 months and progress then evaluated.

Glossary of terms

Blue Badge Scheme	Disabled Parking Badge Scheme for parking concessions for disabled and blind people
Clinical Assessment Team	Often called the CAT – a consultant-led rapid assessment of medical and surgical patients which reduces time taken to reach a diagnosis and commence treatment
Community Mental Health Team	A cross functional team of mental health professionals (e.g. psychiatrist, social worker, occupational therapist, clinical psychologist, pharmacist) offering psychological support, encouragement and practical help to those with various symptoms of mental health
Connecting Carers	Occasional publication published by the ECC Carers Strategy Team
CWOP	Community Wellbeing and Older People Policy and Scrutiny Committee
DAA	Dementia Action Alliance
DoH	(UK Government) Department of Health
ECC	Essex County Council
ERO	Essex Record Office – an Essex County Council facility providing the county’s central repository for resources about the history of the county, its people and buildings
Essex LMC	Essex Local Medical Committee Ltd, which represents local GPs
Essex Reminiscence Network	A project co-ordinated from the ERO and local museums throughout Essex designed to bring pleasure, mental stimulation and meaning to the lives of older people
Forward Look	A programme of work drawn up by the Essex HOSC
GP	General Practitioner
HOSC	Health Overview and Scrutiny Committee
LINK	Essex and Southend Local Involvement Network - a network of local people, organisations and groups to influence the planning and delivery of local services
Memory Assessment and Support Services	Service offering assessment, diagnosis, treatment plan and follow-up through outpatient appointments for adults with memory problems
NEPFT	North Essex Partnership NHS Foundation Trust – an NHS provider of health and social care services for people with mental health problems
NIACE	National Institute of Adult Continuing Education
NICE	National Institute for Health and Clinical Excellence – an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health

NSF	National Strategic Framework for dementia services
OAMH Board	Older Adult Mental Health Board
PBC	Practice Based Commissioning – empowers GP practices and other local health and primary care professionals to develop and commission certain local services
PCT	Primary Care Trust – local NHS organisations that commission services from health care providers
Personalised budgets	A personal budget allocated to an individual, to empower them to purchase their own services within the NHS or through private providers directly
SEPT	South Essex Partnership University NHS Foundation trust – a NHS provider of health and social care services for people with mental health problems and people with learning disabilities
Sundowner Syndrome	Term used for people with dementia who become agitated around time of sunset
Task and Finish Group	A group set up to look at a specific issue within a limited timescale
Thinking Fit	An ECC funded programme to investigate outcomes of actions designed to delay the onset of dementia

THINKING FIT PROGRAMME – CONTACT

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See also www.museumsinessex.org