

Dementia Carer Survey

The effectiveness of local health and social care services

by

**The south east Essex locality of the
Essex and Southend Local
Involvement Network**

Harry Chandler (Chair)
April 2010

What are local Involvement Networks and what do they do?

The Essex and Southend Local Involvement Network or LINK

The Local Government Act of 2007 established Local Involvement Networks in local authorities providing social care services.

The County of Essex and the Borough of Southend-on-Sea decided to create a Local Involvement Network which would be entitled the Essex and Southend Local Involvement Network or LINK to be supported by a Host. This LINK was established in April 2008.

The purpose of the Essex and Southend LINK (E&S LINK) is to work on behalf of the people of Essex and Southend-on-Sea to hold the providers of health and social care services to account. They also assist service providers to commission services appropriate to the needs of the local populations by communicating the views, experiences and needs of the local populations.

Members of the Essex and Southend LINK decided to operate in five localities whose boundaries were coterminous with the Essex Primary Care trust boundaries. This was done to ensure local ownership.

The E&S LINK is wholly independent of the councils. It is a statutory self-organising and self-directing network of local citizens and service users, supported by a Host Organisation – in this case the Council of Ethnic Minority Voluntary Sector Organisations (CEMVO).

The union of the Essex and Southend LINK is based on the principle of devolution as agreed in public meetings after open consultation. The governance framework for E&S LINK should as far as possible devolve normal decision taking and resources to the constitutionally established locality, theme and issue groups. Decisions affecting the whole of Essex and Southend must be taken by a countywide public meeting.

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Members involved with the survey:

Barrie Andrews
Peter Payne
Eddie Camp and
Harry Chandler

Host personnel involved:

Ian Flack

1. Abstract

The south east locality of the Essex and Southend Local Involvement Network (LINK) asked the carers of people with dementia (see appendix 4 for a definition of dementia) about their experiences of the health and social care services in south east Essex. The report is based on the analysis of a questionnaire. The people interviewed were either known to members of the LINK or had been approached by LINK members when they attended meetings of the local dementia cafes and a meeting about dementia care conducted by the Southend Carers Forum. We were able to interview 22 people across south east Essex for their views. The local NHS and Councils had been approached to provide carers for interview. Because of restrictions made by the Data Protection Act and the duty of patient confidentiality, the NHS and councils were unable to provide interviewees. The report is critical of the outcomes for people with dementia using local services and makes suggestions to improve local services.

2. Background to the report

Residents and voluntary organisations of south east Essex, comprising of the Borough of Southend-on-Sea and Castle Point and Rochford Districts of Essex, had expressed concern that local health and social care services were not providing a satisfactory service for both the people suffering from dementia and their carers.

LINK members examined the National Dementia Strategy and were concerned that the implementation of national strategy seemed unlikely to meet local needs.

LINK members agreed to undertake a project to survey a sample of local carers to provide evidence of need which could be of use to local health and social care commissioners to improve local care services.

3. The project brief

To produce a questionnaire which would be used to survey carers of dementia sufferers to establish the effectiveness of local health and social care services, to identify and survey carers experiences of care services, and to produce a report that would assist local commissioners to help them to provide improved care services.

4. How did we select the interviewees?

Members were acquainted with carers who looked after people suffering from Dementia. The carers were each asked if they were willing to participate in a survey using a standard questionnaire (see appendix 5). As the number of carers known to members was low, members investigated ways and means of extending the number of carers to be interviewed. We considered placing advertisements in the local press to contact local carers, another LINK project (the Hospital Discharge Process group) had attempted to use this technique. The advertisements did not produce a response and a member of the Host staff spent a day in our Nelson Street, Southend-on-Sea office without anyone appearing for interview. Accordingly, we did not pursue this approach.

We contacted the local statutory care services and a voluntary organisation, the Southend Carers Forum for their assistance. These organisations had to decline our request because of patient confidentiality issues and because of concerns about breaching the Data Protection Act.

Members decided to attend the recently established Dementia Cafes organised by the Alzheimer's Society as a method of contacting more carers. When members attended the cafes each carer was asked if they were willing to take part in an interview, no one objected. This extended the number of potential responders to the questionnaire from six carers to 24 carers. This approach also meant that we were able to interview carers over a much wider area of south east Essex. We considered that we were now able to start interviewing carers. Our plan was to interview the 24 carers identified over a three week period. Due to the fact that some carers were unavailable, the number finally interviewed was 22. We performed interviews by face to face contact (six carers) and telephone (16 carers) (see appendix 5 for a questionnaire).

In addition to interviewing carers, members attended an event organised by the Southend Carers Forum which was attended by approximately 40 people and this was about support of dementia carers. See appendix 3 for notes taken at the event.

5. Our conclusions

- a) We found little evidence that the National Health Service (NHS) or Social Services provided by local councils made any significant difference to the health and well being of many of the sufferers of dementia or the carers of people who suffer from dementia.
- b) We found that those with dementia relied on their carers. Carers who could have benefited from better support from the statutory care services were not well served by either the NHS or Social Services.
- c) Our observation is that easy access to care services and support to carers is critical to the provision of support to dementia patients. This was not appreciated by many in the statutory services. Perhaps more critically, the national guidance and the local draft work plan do not emphasise adequately the critical role of the carer (see appendix 1 and 2).
- d) We consider that both national guidance and local dementia plans seem to concentrate on longer term issues rather than those which improve the health and well being of our population in the short and medium term. In our view both the guidance and work plans are worthy, but they risk taking the attention of commissioners away from potentially low cost and relatively easy to implement improvements to the lives of patients and their carers.
- e) Our view is that the present care arrangements are fragmented. Services are under considerable pressure and seem to deliver a poor outcome in spite of the large sums of money spent on them. Local services are ineffective for the majority of the population. Should patients and their carers be lucky enough to be provided with the best of all local services, their quality of life will be significantly better than that of the majority who "struggle along", to quote several respondents to our survey. It seems sensible that commissioners provide clear pathways for the delivery of care across all services and to break down the boundaries between the various services. We expect that in addition to improving services there are likely to be knock on cost reductions by taking this approach.

- f) Members are normally cautious about requesting thorough overhauls of care services. We normally support the “build on the best of what already exists” approach as being the safe and certain option. We suggest that improving the support of local dementia patients and their carers is urgent. The present arrangements have grown in a piece meal fashion and in our view offer poor value for money. To build on shaky foundations risks throwing money away with negligible benefit to our population. We believe for the future a thought through “joined up” approach to dementia is essential. The present arrangements seem to result in the whole being less than the sum of the parts. We therefore recommend that the dementia care services need a thorough overhaul.
- g) Our recommendation is treatment for dementia should be community based on a social care model rather than on a health or ill-health model. There is sufficient evidence to indicate that dementia is principally a problem of community social care and should be addressed this way. Some existing community based services are reported by carers we surveyed as performing well and community front line staff are well respected. Outcomes are the best that can be hoped for. Hospital based services seem to perform ineffectively in spite of the strenuous efforts of those that work in them. In many ways they attempt to provide a social care function using an inappropriate care model.
- h) Most respondents to our survey were insistent that they needed a single point through which information about all aspects of dementia could be obtained and that this is needed now. Whilst we are unable to comment on the costs of implementation and operation, our view is that a low cost service should be provided immediately covering all aspects of dementia ranging from what support is available, where help is available and what benefits can be claimed. The information service needs to cover all health, social care and housing and benefit issues. Perhaps this service could be provided through a local voluntary organisation. NHS Choices would seem worthy of investigation as part of an improved delivery mechanism. Carers also need someone to talk to initially. The person should understand dementia and the stress caused to carers, and what can be done to urgently alleviate the stress and offer help to the patient/client and carer.
- i) A summary of the Draft Joint South East Essex Work Plan for Dementia is in Appendix 2. We consider that the work plan is worthy, but unlikely to address the problems of south east Essex that we found in our limited survey. We suggest that the implementation of this plan is unlikely to make a difference to the outcome for dementia patients and carers in south east Essex.
- j) We surveyed a cross section of the population of south east Essex from those who were relatively affluent to those who were severely disadvantaged. We found that all surveyed suffered equally regardless of income. The people who came out best seemed to be those who were familiar with the “system”. They knew what was possible. They were able to use their knowledge to provide better support and a better quality of life for themselves and the people for whom they cared. Our view is that improving the availability of all types of information to dementia carers and patients is critical and is likely to be able to be delivered quickly and at low cost.
- k) The Southend Carers Forum plays a critical role in improving the lives of many carers and their patients. Other voluntary organisations including the Alzheimer’s Society appear to provide significant help to carers and patients. Our view is that the role of the local voluntary organisations should be re-

examined in relation the assistance they can give to carers and patients and where appropriate should be given a higher profile.

6. Survey technique

We decided to use questionnaires to interview carers to facilitate analysis of our findings. After several months of trialling our interview questionnaires using carers known to us in south east Essex and seeking advice from local voluntary organisations such as the Alzheimer's Society, we produced a survey questionnaire (see appendix 5). We also used Internet sources to establish what questions had been used by other surveys, for example by the Alzheimer's Society and the Care Quality Commission.

We asked for each carer to give us their views of the patient's condition and the carer's views of theirs and the patient's experiences of care services. Where possible, we attempted to get "yes/no" answers to survey questions. Where this was not possible, we asked open ended questions about the opinions of carers and encouraged carers to develop their answers to questions.

7. Our findings

This survey is based on a limited sample (22 carers) of the population of south east Essex. It covers carers living in most parts of south east Essex. Our findings are similar over the area.

Whilst we found common themes in the answers to our questions, we noted that each carer had a different experience of caring for a dementia patient and of local health and social care services.

We found carers were very willing to talk about their experiences and welcomed the opportunity to talk about them. Several carers commented that they felt pleased to be interviewed and had benefited from the experience.

A typical comment of a carer's experiences of healthcare services was: "A very negative experience, I felt let down by the NHS; I had to find out everything for myself" – this quote was from a carer after her mother was diagnosed with Dementia in 2009. Regrettably, this view was not uncommon.

Social services also were criticised: "Carers seeking help have no one from the statutory services to talk to. The telephone assessors wish only to speak with the 'patient/client' and no one seems to want to take the carers wellbeing into account." One comment was: "Even when one asks for someone to talk to, there seems to be no one available. I guess that the problem is that trained social workers are in short supply and much of the initial work is done by untrained telephone administrators/ assessors ticking boxes. This leaves the carer in a very worrying and stressful situation. The phone assessment seems to take only the risk factor of the patient/client into account and not the carer".

A typical response of the carer's view of themselves is: "It is a life sentence"

We were disturbed that several carers were in denial about the condition of the person for whom they cared. They became involved with care services when they became unable to cope with their caring responsibilities and wished they had contacted the care services earlier rather than “struggling on”. Many carers informed us that the person for whom they care did not recognise they had dementia. The person cared for resisted all attempts to let care services help them. Several carers said that they wished they had sought help earlier and that their worst problem was getting information to help them. This turned out to be a general problem.

Lack of breaks in caring was frequently mentioned by the carers interviewed. Carers face a dilemma that the person cared for does not want anyone else other than their familiar carer to be with them. Carers feel guilty about leaving the person for whom they care. The result is that many carers do not take breaks or holidays, although they feel they need a break from caring.

The general attitude of carers to the care services is that they were difficult to reach and usually produce disappointing outcomes for the person they cared for when the service had been reached. When the carer makes contact with the relevant service, they find that there is no one to talk to. The telephone assessor seems to have neither the knowledge nor the training to answer carers' questions.

There were wide variations in carers' views of both NHS and Council services, Council Social Services came in for particular criticism. The effectiveness of the Southend Hospital Memory clinic was questioned by many carers. The quality and effectiveness of services provided by SEPT was also queried by many carers. No statutory service came out well from the survey.

Considering all statutory care services, the reaction of the carers we interviewed was that the NHS and councils seemed to be more anxious to save money, than provide an effective care service. When carers needed help, they found they needed to know what question they should ask. Without knowing what to request, they were left in ignorance about what statutory services could do for them. Carers were then frustrated as they felt that help was unavailable.

A particular concern is that carers were generally unhappy with the effectiveness of the GP service. The common observation is that GPs were anxious to send the patient to another part of the NHS and provided little effective support. We were especially disappointed that most GPs had not provided carer annual health check and carers were generally unaware that they were entitled to a carers assessment from Social Services. There would appear to be some confusion around the carers annual health check available from GPs and the carers assessment provided by Social Services. Whilst some carers felt that the Southend Memory Clinic helped patients with dementia, many considered that the Memory Clinic had provided no long term benefit.

Carers felt that they benefited from sharing their experiences with people in similar circumstances to themselves. They were able to share experiences when attending the memory clinic at Southend Hospital whilst the patient

was waiting to be seen by clinical staff. The Southend Carers Forum was known to most people surveyed. Its main effectiveness was to give members the opportunity of meeting carers in similar situations to theirs, to provide information about benefits and to help carers to find contact details of services. Several carers mentioned that the Southend Carers Forum was a real benefit to them.

All carers who had seen the publications produced by the Alzheimer's Society found them to be helpful. The common criticism was that whilst they considered the publications to be excellent in providing medical information, the publications did not help carers to understand how to change their caring approach as the disease progressed. The newly established dementia cafes have been received positively by carers to whom we spoke.

8. Survey results (see appendix 5 for a sample of the form used)

Carers were interviewed mainly by telephone and no names or addresses were recorded by the interviewer to maintain patient confidentiality. The survey form was completed by a LINK member, when the interview took place Carers were encouraged to explain their answers and some comments made by the carers are included in this section.

Our final questions were deliberately open ended. These questions were:

"What single thing/service would improve your life?"
"Any further comments?"

The question: "What single thing/service would improve your life?" proved to be the most difficult one for carers to answer. No-one had ever asked them that question before, which seemed strange.

The question: "Any further comments?" provided some very interesting answers. All answers to these questions are at the end of this section.

At the end of the interview, we were usually thanked for spending our time with the carer they commented that it was an unusual experience. Comments were made along the lines of: "We are glad that someone is taking our problems seriously" or "We are glad that your organisation cares about us, we feel so alone". The comment: "We hope that something positive will come out of the work you are doing" was made by many carers.

The duration of the interview ranged from 20 minutes to about 2 hours.

We have tabulated the survey results for ease of understanding. Where carers made comments about the question being asked, we put a summary of the comments under the table.

a. Carers

Total Interviewed	22
Average Age	71
Maximum Age	86
Minimum Age	49
Females	12
Males	10

b. Patients

Total interviewed	22
Average Age	83
Maximum Age	95
Minimum Age	68
Females	13
Males	9

c. Relationship between carer and patient

Spouse	12
Daughter	8
Son	1
Mother-in-law	1

d. Sole carers

Total sole carers	Total carers
16	22

e. Location of patients

Postcode		Numbers
SS0	Westcliff	2
SS1	Thorpe Bay	3
SS2	Southend	3
SS3	Shoebury	3
SS4	Rochford	1
SS5	Hockley	1
SS6	Rayleigh	0
SS7	Benfleet	1
SS8	Canvey	0
SS9	Leigh	8

f. Residence of Patient

Home	17
Care Home	3
Hospital	1
Sheltered Housing	1

g. Year Patient Diagnosed with Dementia

2000	1	2006	2
2001	2	2007	4
2002	0	2008	4
2003	2	2009	2
2004	2	2010	1
2005	2		

h. Symptoms appearing to diagnosis

Years	Numbers of people
5	2
4	1
3	1
2	4
<1	14

i. Condition of Patient as viewed by the carer

Mild	3
Serious	17
Very Serious	2

j. Help needed by patient

Some Help	4
Substantial Help	9
Continuous Support	9

k. Do you consider that you have sufficient information about dementia?

Yes	15
No	7

l. Where did you get the information?

- Memory clinic
- Balmoral
- From Carers Forum, no information on what will happen
- Had to find out myself
- Own investigations
- Provided by daughter
- Lots of information about dementia. Nothing about how to cope with dementia
- Too much about the disease, too little about emotional reaction.
- Not given any. Got information myself. Nothing on managing the condition.
- As far as I need
- Could keep carer informed of my husbands condition

m. Are you satisfied with the support you get from your GP?

Yes	15
No	7

- Excellent
- Need more help
- Very good
- Not involved
- Very fine
- Stay out of his clutches
- Not satisfied

m. Are you satisfied with the support you get from the psychiatrist?

Yes	9
No	9
Do not have a psychiatrist	4

- Now on the third one
- Too early to say
- Patient does not think there is anything wrong. Listens to the patient
- Not necessary
- Very good

n. Are you satisfied with the support you get from your Community Nurse/CPN?

Yes	8
No	12
Not applicable	2

- Don't want one
- Yes but now stopped
- Pops in occasionally
- No longer provided

o. Are you satisfied with the support you get from your social worker?

Yes	6
No	4
Do not have a social worker	12

- Don't want one
- One coming soon
- Useless
- Not very good
- Poor manner. Waiting for another one
- Patient does not think anything wrong and will not allow the social worker into the house
- Care worker not satisfactory
- Council ineffective

o. Other help

Many carers have no additional help. For those that have help there is a mixture of assistance from:

- The family, brothers and sisters and other family members
- Friends and neighbours
- Private company assistance
- Harland centre
- Help with the house and garden
- Financial advice

p. Use of the Southend Hospital Memory Clinic

Yes	4
No	6
Not aware of the service	12

- Nurse excellent
- Whole approach good
- Diagnosis unprofessional
- Very satisfactory
- Had to wait 4 hours for a 15 minute consultation
- Memory clinic ineffective
- Promises of support did not materialise
- Change of staff

q. Use of SEPT (South Essex Partnership Trust) services

Yes	4
No	5
Not aware	13

- Doing nothing – boring for the patient
- Harland centre excellent
- Cannot get dad to accept he needs a psychiatrist
- Harland OK
- Problems started when transferred to SEPT

r. Do the NHS and the Council work together for you?

Yes	6
No	15
No comment	1

- Independently
- Social worker and discharge OK
- Falling over backwards (we interpreted this as “very well”)

s. Do all parts of the NHS work together for you?

Yes	6
No	13
No opinion	3

- GP does not get enough information from the hospital
- GP does his job
- Community Nurse gave lots of help, but not in the carer’s wife’s case
- Dissatisfied with SEPT
- After memory clinic, some doubt
- GP not interested
- People try hard to make it work
- Poor staffing in Clifton

t. Is the service user taking prescribed medication because of dementia?

Yes	16
No	6

- Tablets given but patient refuses them
- Was Aricept now stopped
- Drugs used by patients
 - Aricept 6
 - Reminyl 4
 - Cerbo marzipan 1

u. Is the medication;

Very effective	3
Quite effective	8
Not at all effective	1
Don't know	4
No medication	6

v. Apart from medication is the service user receiving any other NHS or council services?

Yes	5
No	17

- Day centre
- District nurse
- Weekend treatment
- Harland Centre
- Day Centre
- Peaceful Place

x. Do you have help from voluntary services?

Yes	12
No	10

- Carers Forum
- Alzheimer's society
- Age Concern
- Salvation Army
- Attend groups and meals
- Care home
- Social events and outings

y. Have you had an assessment of your needs by your GP?

Yes	3
No	19

The most frequently expressed opinion to this question is the carer did not want an assessment. Don't need anything. My family work together.

Those that had been assessed said they did not receive any services.

z. Have you (the carer) had a break from care?

Yes	8
No	14

Comments received included:

The family give support. We put mother in a care home. Mother would not want me to. She would object to being left. Do not want one (a break). The Salvation Army looks after the patient. "I feel a break would be helpful". I have not had one. I had a break through SEPT. Father offered a break, but refused. Yes by the patient funding himself.

aa. Did you (the carer) have to pay for respite care yourself?

Yes*	5
No	3
No break from care	14

*Got help through the Council/SEPT.

ab. Does the service user pay for respite care?

Yes*	7
No**	1
No respite care	14

*Through social services

**Not taken up. Inappropriate

ac. Are you aware of the memory clinic?

Yes	18
No	4

ad. How useful is the memory clinic?

- Useful to the patient. He gets medicine
- Very useful
- The clinic acted as a guide to the patient's condition. I objected when they would not continue the service
- Not very
- Trying new tablets
- Not useful
- Able to talk to others. Memory not better
- Somewhat useful
- Helps understand where we are and to take an objective view
- Very satisfactory
- Hospital not useful, SEPT useful.
- Both SEPT and the Hospital were useful. Do not use any longer. The service is performed at the Harland Centre.
- Useless.

ae. Were you advised of any benefits to which you were entitled?

Yes	18
No	4

af. What benefits do you claim?

18 respondents said that they had been advised of benefits that could be claimed, 4 said they were not advised.

The benefits claimed by most of our respondents are;

Attendance allowance and Council Tax relief.

Not all respondents were comfortable with claiming benefits as “we don’t want charity”.

Some respondents said that they found their benefit entitlement by extensive personal research. Others said information was not volunteered and direct questions needed to be asked along the lines of “Am I entitled to attendance allowance?”

ag. Stigma – do you feel that you or the patient are stigmatised as a result of the condition of the patient?

Yes	6
No	16

We had anticipated a majority of the carers to respond that they and the patient were stigmatised. Some carers reported they were stigmatised, but the majority of carers reported that family, neighbours, and friends felt that people felt sorry for the carer and the patient. One adverse comment was “We are stigmatised by some people, Mum feels it”.

ah. Are you aware of Southend Carers Forum?

Yes	18
No	4

The carers’ response was encouraging and carers spoke very highly of the work and support provided by the Carers Forum. Remarks like “I did not get in touch early enough” indicated a high level of satisfaction. One carer said “I do not feel the need”.

ai. What single thing/service would improve your life?

The following are individual responses not grouped or ordered. Some responses are duplicated or very similar.

- Knowing where to get help
- NHS staff to understand dementia
- Respect for the person with the illness
- Someone to pop in and speak to my wife (the patient)
- Joined up health service
- Someone I can phone and discuss issues
- Someone I can talk to and get answers
- More help from other members of the family
- To have a carer (note: this was an answer provided by a carer)
- For my daughter to continue to help
- To go away more often
- Mum to be somewhere where I do not need to worry
- One person to talk to
- Empower a person who cannot remember

- Graduated care which is appropriate to the patient. Supervision with a light touch
- Sort Social Services out
- To have a good Community Psychiatric nurse during the entire illness
- Certainty of continuity of present care
- Single point of reliable information
- Would like a break. Friends to cover for the carer.

aj. Other comments

- My husband is likely to leave the house and get lost. I need security
- Problems of hospital appointments being cancelled
- I have a lot of support from the community
- The biggest problem is to know where to go. Everyone operates individually, not joined up.
- Dementia has been “a very negative experience of the NHS” I feel alone
- Problems with social care add to my problems
- Alzheimer’s Society was non committal they did not answer direct questions
- One source of reliable information
- Carers are confused too
- Problems of getting a patient to the hospital because of his condition
- Need a one-stop-shop to be made aware of all services
- Carers are part of a relationship. What happens is the relationship needs to change
- The system seems inflexible. The patient has to jump through hoops to get to SEPT
- Too many hospital visits
- My husband has deteriorated. I cannot cope. I want a single point to contact health and social care
- Try to improve the social experience at Clifton Lodge. My suggestion is that commissioners spend a week in Clifton Lodge to find out what it is like
- Spot checks rather than pre-announced visits. Permanent staffing rather than constant change of staff

Appendix 1

From: **Living well with dementia – the National Dementia Strategy Joint commissioning framework for dementia** Claire Goodchild published June 2009

Commission services that maintain and enhance an individual's abilities

All services for people with dementia should aim to promote and maintain independent functioning. Including all groups of people affected by dementia

Commissioners are responsible for ensuring that services are provided to all individuals affected by dementia in the local population. Section 2a of the NHS Constitution¹² states that patients: *".....have the right to expect your local NHS to assess the health requirements of the local community and to commission and put in place the services to meet those needs as considered necessary."*

The NDS recommends that the following services should be available locally to all people with dementia.

- Objective 1: Improved public and professional awareness and understanding of dementia
- Objective 2: Good quality early diagnosis and intervention for all
- Objective 3: Good quality information for those diagnosed with dementia and their carers
- Objective 4: Easy access to care, support and advice following diagnosis, facilitated by a dementia advisor
- Objective 5: Structured peer support and learning networks
- Objective 6: Community personal support services
- Objective 7: Services within the Carers' Strategy
- Objective 8: Good quality care within general hospitals
- Objective 9: Intermediate care for people with dementia
- Objective 10: Good housing, housing-related and telecare support
- Objective 11: High quality services within care homes
- Objective 12: Good end of life care
- Objective 13: An informed and effective workforce across all services
- Objective 14: Joint commissioning strategy

Appendix 2

Draft Joint South East Essex Work Plan for Dementia

1. Raise awareness of dementia and encourage people to seek help
2. Good quality, early diagnosis, support and treatment for people with dementia and their carers, explained in a sensitive way
3. Good quality information for people with dementia and their carers
4. Easy access to care, support and advice after diagnosis
5. Develop structured peer support and learning networks
6. Improve community personal support services for people living at home
7. Implement the New Deal for Carers
8. Improve the quality of care for people with dementia in general hospitals
9. Improve intermediate care for people with dementia
10. Consider how housing support, housing-related services, technology and telecare can help support people with dementia and their carers
11. Improve the quality of care for people with dementia in care homes
12. Improve end of life care for people with dementia
13. An informed and effective workforce for people with dementia
14. A joint commissioning strategy for dementia
15. Improve assessment and regulation of health and care systems and of how systems are working
16. Provide a clear picture of research about the causes and possible future treatments of dementia
17. Effective national and regional support for local services to help them develop and carry out the Strategy

Appendix 3

Notes of a meeting of the Southend Carers Forum about carers experiences of Dementia at the Army and Navy Club Southend-on-Sea at 11am on 22nd March 2010

Chair of meeting: Peter Stroudley

Number of attendees: approximately 40

Peter asked those present to consider their experiences under 5 headings.

Note: 1. Throughout the notes, the person cared for is called the "patient".

Note: 2. I have tried to quote the speakers words verbatim.

1. Carers provided their experiences of The First Diagnosis and Initial stages of Dementia

- The patient did things which were out of character. He lost things
- The carer noticed behavioural changes in the person cared for
- At diagnosis, the carer was devastated. The GP communicated the diagnosis in front of the patient.
- There were 3 mentions of insensitive GPs at diagnosis of dementia.
- The GP's advice was to go to a help group. The GP could do nothing
- Another carer complained that GPs were too insensitive and "threw" things at the carer and the patient.
- GPs do not understand Alzheimer's disease. Nurses in the Hospital did not understand Alzheimer's either
- The GP commented: "What do you want me to do about it?"
- I needed care and support from the beginning. The first question should be: "What can we do for you?"
- Social workers are no use
- "I need help to get the patient to co-operate and avoid being difficult".
- "Do patients have a right to know about their condition?"
- "There are parallels with cancer. Both evoke fear. To say that "you have dementia and there is nothing we can do about it is not acceptable, there is something that can be done." The McMillan Nurse cared for my mother with dementia.
- The patient "would not acknowledge there was anything wrong."
- "All that is wrong with my wife is she has a bad memory. Do not say there is nothing wrong with you".
- "The doctor said: "Nothing is wrong with your Mum". She had memory tests which confirmed she had dementia.
- "The Social Worker is no help".

2. What support have you had as a carer?

- I spoke to Social Services 18 months ago. There has been no support or contact.
- The patient is passed from person to person
- The GP no use.
- The Hospital is no real use
- Patients refuse to go to the Hospital

- I was never asked what support I need. I have no support from anyone except the Carers Forum.
- No one in Hospital pointed to what benefits or care I could get
- “All I know about Vascular Dementia, I got from the Internet”
- “Patient confidentiality is used as a get out.”
- “Dr. Liakus is brilliant”. So much help from the Carers Forum”. “Christine Timms is excellent.”
- “I was given leaflets and told to do this and that”
- The GP’s diagnosis is: “just old age.” There was no suggestion of the memory clinic.
- The GP Practice Manager was sympathetic.
- The CPN (Community Psychiatric Nurse) was marvellous
- My GP was condescending.
- “I have only heard of the Memory Clinic since coming to these meetings.”
- I was not informed by the GP how loved ones are going to change.
- Information comes from my daughter. “My daughter she is an Occupational Therapist – no one else.”
- I had no support from anyone. No paper, no books. I have learning difficulties. I was told: “get on with it.”
- “The people who really help are the Alzheimer’s Society, not the GP”.
- “I want one piece of paper which tells us what to do”.
- “I was not consulted when Mum went into full time care. If Mum falls over, tell me. I was not told.”

2. Have you made any plans for the future?

- Living will
- Lasting power of attorney – if the person has a mental problem.
- Write wills
- Tenants in common
- Court protection of money

3. Arranging breaks for the carer.

- A good Social Worker can help. “As good as the person that walks through the door.”
- The only way to get help is from SEPT.
- One out of 40 got a break organised by a Social Worker
- Carers Forum
 1. Prescribed break by a Social Worker
 2. Flexi breaks
- People with Alzheimer’s need the same person (when the carer is not there)
- “I tend to use friends rather than a Social Worker because the staff change all the time.”
- “I had to fix everything for myself.”
- “It has got to be the same person.”
- “I went through a private company and got a continuous person”
- “I used Crossroads and found them to be very good.”
- “We have used Crossroads and they are excellent, but they are expensive.”
- “I cannot consider a break because my Mum would not let another person through the door.”

- “My husband would not let a carer through the door and I became housebound.”
- When a carer was looking after my husband “my husband said no” so he had nothing to eat. “If you put food in front of him, then he will eat it.”

4. Modifications to the house

- A waiting list of 18 months for a wet room.
- “Where do I go for advice? My GP, the council”
- “The assessment covers all issues. The Social Worker can cover all issues”
- “The best way of getting round the loop is via the SEPT team”
- “I have been waiting 18 months for a Social Worker”
- “They talk to the patient, not the carer”

5. You are in the advanced stage of dementia, how do you cope?

- “The big problem is at night. I can get help during the day. My husband puts all the lights on and returns to bed and puts the lights on again and then goes down stairs again”
- “My husband cycled off and finished in Rochford Hospital. The police found him”
- “I put a band on his wrist with his name, telephone number and Alzheimer’s”
- “Hospice at Home helps people at night to stay in their own home”
- “Every single person with Alzheimer’s is different”
- “Social Workers do not understand Alzheimer’s.”
- The Citizens Advice Bureau is a great help with benefits etc. SAVS are helpful with forms
- The objective should be to extend the period when everything is normal.”
- A relatively passive phase, followed by a personality change which is very stressful.”
- Lack of information is the key problem.
- “Peaceful Place specialises in dementia. Why can’t other centres be the same?”
- South East Essex Advocacy can help.
- The help for the over 60s is better than for younger people.

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Appendix 4

Alzheimer Society publication extract

What is dementia?

If you, or a friend or relative, have been diagnosed with dementia, you may be feeling anxious or confused. You may not know what dementia is. This fact sheet should help answer some of your questions.

The term 'dementia' is used to describe the symptoms that occur when the brain is affected by specific diseases and conditions. These include Alzheimer's disease and sometimes as a result of a stroke.

Dementia is progressive, which means the symptoms will gradually get worse. How fast dementia progresses will depend on the individual. Each person is unique and will experience dementia in their own way.

Symptoms of dementia include:

- Loss of memory – for example, forgetting the way home from the shops, or being unable to remember names and places, or what happened earlier the same day.
- Mood changes – particularly as parts of the brain that control emotion are affected by disease. People with dementia may also feel sad, frightened or angry about what is happening to them.
- Communication problems – a decline in the ability to talk, read and write.

In the later stages of dementia, the person affected will have problems carrying out everyday tasks, and will become increasingly dependent on other people.

What causes dementia?

There are several diseases and conditions that cause dementia. These include:

- **Alzheimer's disease** – The most common cause of dementia. During the course of the disease the chemistry and structure of the brain changes, leading to the death of brain cells (see [Factsheet 401, What is Alzheimer's disease?](#)).
- **Vascular disease** – The brain relies on a network of vessels to bring it oxygen bearing blood. If the oxygen supply to the brain fails, brain cells are likely to die and this can cause the symptoms of vascular dementia. These symptoms can occur either suddenly, following a stroke, or over time through a series of small strokes (see [Factsheet 402, What is vascular dementia?](#)).
- **Dementia with Lewy bodies** – This form of dementia gets its name from tiny spherical structures that develop inside nerve cells. Their presence in the brain leads to the degeneration of brain tissue. Memory, concentration and language skills are affected. This form of dementia shares some characteristics with Parkinson's disease (see [Factsheet 403, What is dementia with Lewy bodies?](#)).

- **Fronto-temporal dementia (including Pick's disease)** – In fronto-temporal dementia, damage is usually focused in the front part of the brain. At first, personality and behaviour are more affected than memory (see [Factsheet 404, What is fronto-temporal dementia, including Pick's disease?](#)). Rarer causes of dementia

There are many other rarer diseases that cause dementia, including progressive supranuclear palsy, Korsakoff's syndrome, Binswanger's disease, HIV and AIDS, and Creutzfeldt-Jakob disease (CJD) (see Factsheets [438, What is Korsakoff's syndrome?](#), [446, What is HIV-related cognitive impairment?](#) and [427, What is Crutzfeldt-Jakob disease?](#)). People with multiple sclerosis, motor neurone disease, Parkinson's disease and Huntington's disease may also be more likely to develop dementia.

Mild cognitive impairment

Some individuals may have difficulty remembering to do things, but a doctor may feel that the symptoms are not severe enough to warrant the diagnosis of Alzheimer's disease or another type of dementia. When this condition occurs, some doctors will use the term 'mild cognitive impairment' (MCI). Recent research has shown that a small number of individuals with MCI have an increased risk of progressing to Alzheimer's disease. However, the conversion rate from MCI to Alzheimer's is small (10-15 per cent), so a diagnosis of MCI does not always mean that the person will go on to develop Alzheimer's.

Who gets dementia?

- There are about 700,000 people in the UK with dementia.
- Dementia mainly affects older people. However, it can affect younger people: there are 15,000 people in the UK under the age of 65 who have dementia.
- Dementia can affect men and women.
- Scientists are investigating the genetic background to dementia. It does appear that in a few rare cases the diseases that cause dementia can be inherited. Some people with a particular genetic make-up have a higher risk than others of developing dementia.

Can dementia be cured?

Most forms of dementia cannot be cured, although research is continuing into developing drugs, vaccines and treatments. Drugs have been developed that can temporarily alleviate some of the symptoms of some types of dementia. These drugs are known as acetylcholinesterase inhibitors.

The National Institute for Health and Clinical Excellence (NICE) revised guidance on acetylcholinesterase inhibitors to treat some types of dementia, issued in 2006, recommends that people in the moderate stages of some types of dementia should be given treatment with one of these drugs.

Alzheimer's disease

People with Alzheimer's disease may be offered an acetylcholinesterase inhibitor if their non-cognitive symptoms are very distressing and other treatments have not worked or are not suitable.

Dementia with Lewy bodies

People with dementia with Lewy bodies may be offered an acetylcholinesterase inhibitor if their non-cognitive symptoms are very distressing.

Vascular dementia

People with vascular dementia should not be offered an acetylcholinesterase inhibitor, except as part of a clinical trial.

The three acetylcholinesterase inhibitor drugs are:

- Aricept (donepezil hydrochloride)
- Exelon (rivastigmine)
- Reminyl (galantamine).

A further drug Ebixa (memantine) was developed to help people in later stages of Alzheimer's disease. It is licensed for use in the UK but NICE does not recommend it as an option for people with moderately severe to severe Alzheimer's disease unless it is being used as part of a clinical trial (research).

How can I tell if I have dementia?

Many people fear they have dementia, particularly if they think that their memory is getting worse. Becoming forgetful does not necessarily mean that you have dementia: memory loss can be an effect of ageing, and it can also be a sign of stress or depression. In rare cases, dementia-like symptoms can be caused by vitamin deficiencies and/or a brain tumour. If you are worried about yourself, or someone close to you, it is worth discussing your concerns with your GP.

Diagnosing dementia

It is very important to get a proper diagnosis. A diagnosis will help the doctor rule out any illnesses that might have similar symptoms to dementia, including depression. Having a diagnosis may also mean it is possible to be prescribed drugs for Alzheimer's disease. Whether you are someone with dementia or a carer, a diagnosis can help you prepare and plan for the future.

Dementia can be diagnosed by a doctor, either a GP or a specialist. The specialist may be a geriatrician (a doctor specialising in the care of older people), a neurologist (someone who concentrates on diseases of the nervous system) or a psychiatrist (a mental health specialist). The doctor may carry out a number of tests. These are designed to test the person's memory and their ability to perform daily tasks.

Can dementia be prevented?

At present, we are not sure what causes most of the diseases that lead to dementia. This means it is difficult to be sure what we can do to prevent dementia itself. However, the evidence seems to indicate that a healthy diet and lifestyle may help protect against dementia. In particular, not smoking, exercising regularly, avoiding fatty foods and keeping mentally active into old age may help to reduce the risk of developing vascular dementia and Alzheimer's disease.

For details of Alzheimer's Society services in your area, visit

alzheimers.org.uk/localinfo

For information about a wide range of dementia-related topics, visit

alzheimers.org.uk/factsheets

Factsheet 400

Last updated: March 2010

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Reviewed by Dr Nicholas MacInnes, Research Fellow, Alzheimer's Society

Appendix 5

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Dementia/Carer Survey – Version 6

Your Postcode	Age	Sex	Relationship to person cared for	Age	Sex	Comments
1. Year person diagnosed with Dementia						
2. Time from symptoms to diagnosis						
3. In your view is the patient's current condition Mild/ Serious/ Very serious						
4. Does the patient need Some help/ Substantial help/Continuous support						
5. Normal residence of person cared for Home/Care Home/Hospital/Other						
6. Are you the sole carer? Yes/No						
7. If the answer to Q6 is No please give details						
7. Do you consider you have been given enough information about dementia Yes/No						
8. Are you satisfied with the support you get from: - Your GP Yes/No						
Psychiatrist Yes/No						
Community Nurse/CPN Yes/No						
Social Worker Yes/No						
Other Yes/No						
Southend Hospital Yes/No						
Hospital Memory Clinic Yes/No						
SEPT Yes/No						
Do the NHS and council work together for you Yes/No						
Do all parts of the NHS work together for you Yes/No						
9. If an answer(s) in Q 8 is No please give details						
.....						
.....						
10. Is the Service User taking prescribed "dementia" medication Yes/No						
11. In your view is this medication Very effective Quite effective Not at all effective						
12. Apart from medication is the service user receiving other "treatment"/services Yes/No						
13. If the answer to Q12 is Yes please give details						
.....						
14. Have you had any help from voluntary services e.g. Alzheimer's Society Yes/No						
15. If the answer to Q14 is Yes please give details						
.....						
16. Have you ever received an assessment of your needs Yes/No						
17. Did you receive services in accordance with the assessment Yes/No						
18. Have you ever been provided with a break from care (respite) Yes/No						
19. If so, please give details.....						
.....						
20. Did you have to pay for respite care for yourself Yes/No						
21. Does the service user pay for respite care Yes/No						
22. Are you aware of local NHS Memory Clinic Services Yes/No						
23. If the answer to Q22 is Yes - how useful is the service						
.....						
24. Were you advised of any benefits to which you are entitled Yes/No						
25. Which benefits do you claim						
.....						
26. If you use "telecare" was your experience satisfactory Yes/No						
27. If the patient required emergency care/assistance was your experience satisfactory Yes/No						
28. If the answer to Q27 was No please give details						
.....						
29. Do you feel fully involved in decisions concerning care Yes/No						
30. Do you feel understood by your friends and neighbours Yes/No						
31. If the answer to Q29 was "No" please give details						
.....						
30. Do you feel that you and the patient are stigmatised because of dementia Yes/No						
31. What single additional thing/ service would improve life for yourself						
.....						
32. Are you aware of Southend Carers Forum services Yes/No						
33. Any further comments						
.....						
.....						

Thank you for your help in this important survey.

Harry Chandler Chair SE Locality of the Essex and Southend Local Involvement Network