

## **Epping Forest Review by Task and Finish Panel**

Questionnaire on Service Provision by SLA Funded Groups

Report by Marion Howell, Services Manager, Alzheimer's Society, West Essex

### **1. Name of Group**

Alzheimer's Society

### **2. What does your group do?**

The Alzheimer's Society is the UK's leading care and research charity for people with dementia and those who care for them. It is a membership organisation, which works to improve the quality of life of people affected by dementia.

We aim to reach out to people with dementia and their carers across the Epping Forest area, offering specialised information and support services. We aim to ensure that all people with dementia, their carers and families are informed about how to live well with dementia and are supported to remain in their own homes for as long as possible. We offer a range of support services which aims to provide social and emotional support, prevent isolation, and facilitate shared experiences which will enable people to live well with dementia.

### **Please tell us about the positive impact you feel you make in the Epping Forest District**

Dementia is one of the most common and serious disorders in later life. Dementia causes irreversible decline in global, intellectual and physical functioning. The Dementia 2014 Report highlights that dementia is the most feared health condition for people over the age of 55, but touches people of all ages. The negative impact on people with dementia and their family carers is profound. At a national level, the economic cost of caring for people with dementia is immense, with direct costs estimated to be around £26 billion each year – higher than cancer, heart disease or stroke. The report estimates that approximately 670,000 people in the UK act as primary carers for people with dementia, which saves the state £11 billion per year.

The Alzheimer's Society Dementia 2014 Report (2014) identified that there are 1,888 people living with dementia in Epping Forest in 2014. The majority of people with dementia have at least one carer, it can therefore be assumed that there are currently around 4,000 people in Epping Forest, many of whom are frail and elderly, who are experiencing the impact of dementia on a daily basis.

The Government has set year on year targets to improve national diagnosis rates, aspiring to reach 75% of the estimated people with dementia by 2017. In 2013 it was estimated that 809 people had a diagnosis of dementia in Epping Forest (47.5% of the estimated prevalence figures). It is therefore anticipated that a further 1,079 people in Epping Forest will be diagnosed with a form of dementia within the next year to aspire to meet this target. As a result of the drive to increase diagnostic rates, the Alzheimer's Society has seen a significant increase in the number of people being diagnosed with dementia in the Epping Forest area over the past 12 months. The people referred to the Alzheimer's Society's Memory Clinic service for post-diagnosis support has increased by 69% between 2013/4 and 2014/5.

Research has shown that with the right intervention and support, those experiencing dementia and their carers can continue to live independent and active lives. A diagnosis of dementia does not have to mean losing quality of life. The key to good management of the condition is accessing support and information throughout the progression of the condition.

The Services that we offer Epping Forest residents include:

### **Post Diagnosis Support Service**

The Alzheimer's Society Dementia Support Services is based at the Epping Forest Memory Clinic, which provides information and support to people immediately following diagnosis. We meet with a person with dementia and their carer, at Outpatients, when they received their diagnosis. We then meet families at their home and provide high quality and comprehensive information on all aspects of dementia and local and universal support services offered by the Alzheimer's Society along with information about statutory services in the area. We give people the opportunity to think about planning ahead and making informed decisions about future health and social care needs, as well as personal finances. There is clear evidence that post diagnostic support improves the quality of life of people living with the condition and there is also increasing evidence that investment in post diagnostic services is cost effective. A total of 386 people were supported by this service between April 2014 and March 2015. This service is funded by West Essex Clinical Commissioning Group.

### **Community Dementia Support Service**

Families are then referred by the Memory clinic service to our Community Dementia Support Service. The Alzheimer's Society Dementia Support Service provides a unique information, advice, signposting and support for people with dementia and

their carers throughout the course of the condition in the Epping Forest area. A diagnosis of dementia means a gradual process of adjustment for the person with dementia and their carer/s, a process during which access to information and support is vital. Having the opportunity to talk about their concerns, either at their home or over the phone, from diagnosis onwards to a trusted independent, and knowledgeable adviser may help many people to understand their dementia, to plan ahead and find out about the support and services that are available to them, which is essential if they are going to live well with dementia in the Epping Forest area. Dementia can be complex and unpredictable and it is important that people are aware we can provide support at any time. This service has supported 256 people between April 2014 and March 2015. It is funded by Essex County Council.

### **Dementia Cafes**

We also run 2 dementia cafes a months in the Epping Forest area. These are informal drop in style cafes which provide information and advice on strategies on coping for people living with dementia and their carers, as well as information for the general community and those working in dementia care. The cafes take place on the 1<sup>st</sup> and 3<sup>rd</sup> Monday of each month at the Methodist Church in Loughton between 10 – 12 noon. These are funded by Essex County Council and we also receive a grant from Loughton Town Council to cover venue hire. A total of 277 attendances have been recorded at the cafes over the period April 2014 to March 2015.

### **Activity Groups**

We also run activity groups each week for people with dementia. These take place each Thursday at the Quakers Meeting House in Epping. The themes of the groups are Keeping Active Together and Active Minds, both of which concentrate of factors that may help to support physical and mental stimulation which may, have a positive impact in helping people to sustain their health for as long as possible. Weekly breaks also give carers a much deserved break in their caring role. In the year 2014/5, the groups were funded by a national Trust, along with client contribution. Over the year 2014/5 49 sessions of each group were delivered, with a total of 26 people benefiting from the sessions. We have recorded 1333 attendances from 26 people at both groups over the 12 month period. 7 people have left because their needs had progressed and 4 moved to residential care and 3 to a dedicated day support service. This service has a waiting list.

### **Singing for the Brain**

Our trademark Singing for the Brain service is extremely popular, attracting around 30 people per session. It builds upon the fact that people with dementia can still remember music when they are finding the spoken words difficult to communicate and remember. It is a very uplifting hour and a half for people with a diagnosis of

dementia and their carers. It takes place on a Tuesday at the Jack Silley Pavillion. This service is shared with Harlow, with a 12 week rotation between the two areas. There were 313 attendances at the groups between April 2014 and March 2015. However demand has significantly grown since that time and we are now having around 24 people attend each session and are moving towards creating a waiting list for this service. This service is funded by Essex County Council.

### **Dementia Connections**

We also work with Age UK to deliver a social inclusion/enabling service which provides short term active befriending for people with dementia. This is funded by Essex County Council

### **Carers Support**

Carers are the most valuable resource in dementia care. Carers often neglect their own health and needs because of their caring responsibilities. We are aware that all carers are now able to be referred for assessments in their own rights. However, the Alzheimers Society can help with providing social support and information.

### **Carers Information and Support Programmes**

Nobody knows how relentless the role of caring for someone with dementia like other carers. We provide 2 levels of carers information and support courses (CrISP), which are funded by Epping Forest District Council, to take carers through the information they need firstly at diagnosis which looks at planning ahead, information about why people behaviour in the way that they do and encouraging carers to look after themselves and we have a second course which is aimed at people whose relatives may have been diagnosed 18 months to 2 years later. Both are highly valued by carers. They feel that the increased information they have received on the course and their involvement with other carers has been influential in understanding their relative and managing their condition. 39 carers have attended this service over the period April 2014 to March 2015.

### **Carers Support Group**

We also think it is important that carers should have the opportunity to talk about their feelings and for this we provide our carers support group, Care to Talk. It meets on the second Monday of every month at the Methodist church in Epping. Here we encourage carers to provide strategies that help each other and we always say to them do not try to do this alone. We help carers to know more about the condition, but take things at their pace. Friends often disappear after people are diagnosed with dementia. We have much to understand about why dementia remains outside the realms of acceptable conversation. This can result in the family feeling very isolated and alone. There is good evidence that social interventions can

improve outcomes for carers and there is support in the community if we know where to obtain it. There have been 122 attendances at this group over the period April 2014 – March 2015. This is funded by Essex County Council.

In conclusion, the Alzheimer's Society recognise the individual needs that people with dementia may have and want to help them to access support throughout the duration of their condition. We also understand the needs of carers and through low costs, community based activities can help them to sustain their caring role for as long as they feel it is possible.

### **Tell us how the grant aid has contributed to your activities/services**

The grant aid has enabled us to deliver 4 Carers Information and Support Programmes over the year 2014/5. A further 4 courses are planned for the current year. The courses are attended by up to 12 carers at each course. CrISP 1 runs for 5 weeks and CrISP 2 runs for 4 weeks.

### **What would your group like to do to extend its provision and what unmet needs are you aware of?**

We require additional resources within our Community Dementia Support team. Our Memory Clinic service has sustained a year on year growth in the number of people referred to it since it was launched in 2010. However, last year the increase in referral rates was significant due to the Government targets. In Epping Forest, the increase in referrals against the previous year was 69% more referrals than they had received during 2013/14. We applied to the West Essex Clinical Commissioning group for increased resources to address this increase and we were allocated an additional 21 hours of staff time to meet this demand.

However, once the Memory Clinic service has delivered the post diagnosis support, people with dementia and carers are referred to our Alzheimer's Society Community Dementia Support Team based team, which are based at our local offices. Essentially, the two services dove-tail to enable people to access home visits or face to face meetings, information, support, and advice to help them to live well with dementia throughout the course of the condition.

Many people with dementia are now living for longer than a decade with their illness, and they and their families have to cope with changing abilities, fluctuating impairment and make decisions about major life events and circumstances as well as day to day situations. We believe people with dementia and carers deserve high quality specialist support throughout the course of the condition and currently the Alzheimer's Society is the only organisation that offer continuous support in the West Essex area.

Currently, we are contracted by Essex County Council to deliver the Community Dementia Support Service. However, our Epping team is only resourced to deliver 20 hours of dementia support a week.

This is because the allocation of resources within the Essex County Council contract were based on ECC's prevalence statistics at the time the contract was released for the tender process in 2012. They allocated the 56 hours of Dementia Support in the West Essex area on the basis of prevalence in West Essex at 2655 people with dementia. However, the Department of Health figures, as identified in the Alzheimer's Society report Dementia 2014, estimates that there are now 4006 people with dementia in the area. Epping Forest was allocated 20 hours per week as part of this 56 hour allocation and resources are now becoming extremely stretched. This is unlikely to change until 2016/17. As stated previously due to the significant increase in referrals to our services, we are finding that there is a considerable gap between the level of need that is evident and the resources we have to provide on-going support to people with long-term, complex and unpredictable needs. On 7<sup>th</sup> May 2015, the results of a GP on line survey reported that GPs were critical of the controversial £55 payments made to GPs for every referral of a diagnosis of dementia between October 2014 and March 2015 because 83% of the 424 GPs surveyed said that there was not enough support available to patients after a dementia diagnosis. We do not want this to be the case in Epping Forest.

In addition, we would like additional resources to extend our Singing for the Brain service, for which there is a significant demand. We would like to be able to offer the 1.5 hours a week to provide a dedicated Epping Forest area service and not rotate the service with our neighbours in Harlow.

## **Conclusion**

David Cameron has predicted that there will be a cure by 2025. In recent weeks we have heard encouraging news about advancements in treatments. However, at the moment a diagnosis of dementia opens itself to limited medical interventions, but it is important that it opens the door to post diagnostic support for people with dementia and their carers.

Marion Howell

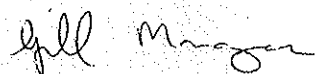
## Summarised financial statements

For the year ended 31 March 2014

## Reporting on summarised financial statements

	2014 Group £'000	2013 Group £'000
<b>Income and expenditure</b>		
<b>Income</b>		
Grants and contracts	31,447	27,452
Legacies	14,733	13,040
Subscriptions, donations and fundraising	30,295	25,013
Investment income	898	697
Other income including trading	5,248	4,569
<b>Total income</b>	<b>82,621</b>	<b>70,771</b>
<b>Expenditure</b>		
Meeting needs	47,526	44,418
Sharing information	2,827	2,264
Advancing research	3,965	5,846
Inspiring change	6,570	5,029
Fundraising	12,427	10,323
Trading costs	1,065	1,517
Governance	319	336
<b>Total expenditure</b>	<b>74,699</b>	<b>69,733</b>
<b>Balance sheet</b>		
Fixed assets	29,968	28,571
Current assets	33,578	25,257
Creditors – falling due within one year	(14,939)	(16,515)
Creditors – falling due after one year	(6,146)	(4,798)
Provisions for liabilities and charges	(563)	(355)
<b>Net assets</b>	<b>41,898</b>	<b>32,160</b>
<b>Funds</b>		
Restricted	9,828	8,327
Unrestricted	32,070	23,833
<b>Total funds</b>	<b>41,898</b>	<b>32,160</b>

The information on this page is extracted from the Trustees' report and annual accounts 2013/14 which has been audited by Crowe Clark Whitehill LLP who gave an unqualified audit opinion on 9 September 2014. The auditors have confirmed to the Trustees that these summarised financial statements are consistent with the full financial statements contained in the Trustees' report and annual accounts 2013/14. The Trustees' report and annual accounts 2013/14 was approved by the Trustees and signed on their behalf on 9 September 2014. The Trustees' report and annual accounts 2013/14 will subsequently be submitted to the Charity Commission and the Registrar of Companies. These summarised financial statements may not contain sufficient information to gain a complete understanding of the financial affairs of the charity. The Trustees' report and annual accounts 2013/14 may be downloaded from [alzheimers.org.uk](http://alzheimers.org.uk)



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