

HOSC/25/10

Committee Health Overview and Scrutiny – Dementia Task and Finish Group

Date 25 November 2010

A written submission received from the Alzheimer's Society is attached.

Health Overview and Scrutiny Committee: Dementia Task and Finish Group.

Comments from the Essex Locality of the Alzheimer's Society on the experience of People with Dementia and their carers.

- Receiving a diagnosis – There are still discrepancies for people obtaining a diagnosis of Dementia. We have experience of individuals not receiving a prompt diagnosis, G.P's who put memory problems purely down to age or are not experienced or confident to diagnose, sometimes a diagnosis is made during a hospital admission without a full assessment. However, Memory services across Essex have developed and many people are receiving their diagnosis in a more timely manner. The Society currently supports Memory Services in Mountnessing Court, Crystal Centre, St Margaret's Hospital, Princess Alexandra Hospital and Brentwood Resource Centre. Patients are appreciating prompt referrals and pathways through this service and also the timely support and information that can be provided by both Memory Service staff and Alzheimer's Society staff.
- Good Quality and prompt information – Carers and people with dementia are still struggling to obtain information about their condition, services and benefits. Many voluntary organisations provide signposting to both statutory and voluntary services to enable people to receive information and support. However, obtaining the right information can be difficult. There remain difficulties speaking to the right department and being 'passed around' until someone deals with the call, continual explanations about individual circumstances when negotiating between health and social care, understanding how decisions are made regarding benefits and care needs. There are some improvements but Carers still find it difficult to negotiate around the benefits system and care systems. The Alzheimer's Society do provide a range of information in a variety of formats. Staff visit both carers and cared for to discuss the condition, coping strategies and the future, this support is on-going and for as long as appropriate, we also work alongside other voluntary groups and the statutory sector to support clients and people with dementia to access a variety of services.
- Personalised Budgets – We actively encourage carers and people with dementia to move towards having a personalised budget. We believe this gives people more freedom to decide on their needs and how those needs will be met. There is a lot of work still going on in this area, but after our recommendations, many Carers report that Social Workers are not providing this option or are still not confident to support a move towards personalised budgets.

- Caring for Carers – there has been a lot of focus on the carers recently. But carers are still struggling with the basics and practicalities of being a carer. Respite can be patchy, often carers want a few hours a week to do shopping, have their hair done etc. this can be difficult to arrange and often what is offered is not what the carers need. Lengthier respite can also be difficult, there are limited respite beds when you consider the quantity of carers that actually want to use them so planning for ‘time off’ can prove problematic as often the time the carer needs cannot be provided. Carers often give up trying to get respite as it can prove too time consuming to keep chasing Social workers etc. to get dates and places. In addition, trying to get respite to cover Carer hospital appointments etc is very difficult to organise, there are however some voluntary groups who provide a ‘sitting service’, and there is also the issue when a carer has an unplanned hospital admission. We are aware of carers refusing to go into hospital as there is no provision for their cared for. Whilst not always considered respite, carers are struggling to obtain Day care services in many areas. Places are limited and many do not provide care and support for people with dementia. Carers do access voluntary group’s activities. The Alzheimer’s Society provide many groups across Essex but only a few offer a service that can be likened to a Day service.
- Training and understanding – Carers and people with dementia report negatively regarding care provided by ambulance and acute sector staff. We are about to start training some Ambulance and front line staff in South Essex, but there remains little training for these staff to enable them to care appropriately for people with dementia. Issues include poor communication, unmet physical and emotional needs. In addition to the Health service staff, the general public knowledge also poses problems for carers and people with dementia, more information provision is required to ensure the general public’s attitude to mental health becomes more positive and inclusive. The Alzheimer’s Society has at present an Information worker who has worked across Essex at many events and venues to raise the public awareness, it has been well received but more is needed to ensure that attitudes and understanding moves forward.
- Care/Nursing Home provision. There is a lot of variation in the levels of care provided to people with dementia. Carers experience a lot of distress when making a decision to let go of the caring role, often the decision is made for them. There is little support for a carer when this decision is made and the subsequent weeks that follow. Whilst those who are supported by voluntary organisation continue to receive that support, many carers are not so well supported. There are many concerns regarding levels of care and ability of care home staff. There needs to be more training, information and support for care homes to enable them to provide safe, secure and enabling environments for people with dementia. The Alzheimer’s Society in Essex does support care homes, we promote our training packages and in South Essex are about to embark on a 3 month project with SWENHS and 10 care homes to look at training and reduce antipsychotics. We also provide awareness raising within the homes and offer to speak to staff and visitors.

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