

ADULT SOCIAL CARE AND HEALTH SCRUTINY COMMITTEE

SUPPORT FOR OLDER PEOPLE AND DEMENTIA
TASK AND FINISH REVIEW 2010-2013

FINAL REPORT

Foreword



Cllr Miss C. Andrew



Cllr Mrs S. Jones



Cllr Mr A. Moran

This report has taken a long time to come to fruition and, along the way, elections reduced the membership of the group from seven to three. We were ably steered through this lengthy and complicated task by Scrutiny Officer Denise French to whom we convey our thanks and appreciation.

We embarked on this task in response to an alarming statistic that in excess of 5000 people in South Cheshire could be suffering from dementia by 2020. How are we coping with dementia sufferers and their carers at present? Have we the capacity to cope with future demand? What is the nature of the need and how effectively is it being met? Finding answers to these and many more questions has been a daunting task as at the outset we did not realise how little we knew about dementia and the complexity of provision and its delivery. The learning curve has been extremely steep.

Our thanks must go to all the people who gave us valuable information and insight into this complex problem. We see this report as a means of identifying the initial actions required to address our main findings and as a springboard for further research.

Cllr Shirley Jones

Chairman

1.0 Membership and Terms of Reference

1.1 The former Health and Adult Social Care Scrutiny Committee set up a Task/Finish Group with the following terms of reference:

- (1) To consider whether the Council, the NHS and Voluntary Sector responses to dementia are adequate to meet the challenge of the ageing population in Cheshire East, in particular:
 - (a) whether there are sufficient preventative services in place
 - (b) whether a personalised approach is suitable for people with dementia
 - (c) whether the provision in health and social care is suitable and sufficient for the more advanced dementia conditions
 - (d) whether the needs of carers are being assessed and met effectively
 - (e) whether there are any gaps in services and support and, if so, how these might be addressed through the relevant bodies' development plans
 - (f) whether there are any specific transport issues arising from current services and future provision
 - (g) what safeguarding provisions are in place and what monitoring arrangements are made
- (2) To consider the broader implications of the current Age UK review of provision in day services, and the proposed transfer of resources to the Supporting You programme.
- (3) To consider and review specific proposals under the Council's Dementia Strategy, including proposals involving residential accommodation, and to advise the Cabinet accordingly.

1.2 This Group was reconstituted by the Adult Social Care Scrutiny Committee in 2011 with the following membership -

- Councillor Shirley Jones (Chairman)
- Councillor Carolyn Andrew
- Councillor Arthur Moran

2.0 What is Dementia?

2.1 Dementia is a term used to describe various different brain disorders that have in common a loss of brain function that is usually progressive and eventually severe. There are different types of Dementia, with the most common being Alzheimer's disease, vascular dementia and dementia with Lewy bodies, but all types of Dementia cause similar symptoms including:

- (1) Confusion
- (2) Changes in mood, behaviour and personality
- (3) Loss of memory
- (4) Loss of interest in life

2.2 Diagnosing Dementia is often difficult, particularly in the early stages. Some of the first signs include lapses in memory and difficulty in finding the right words, memory problems such as not remembering names and places, changes in mood and finding it hard to communicate by a decline in the ability to talk, read or write. Methods of assessment, where Dementia is suspected, can include conversations with the person being diagnosed and those close to them, a physical examination, memory tests and/or brain scans. (source: Alzheimer's Society)

3.0 Dementia - the national picture

3.1 According to the Alzheimer's Society, key dementia statistics include:

- There are currently 800,000 people in the UK with Dementia;
- There are over 17,000 younger people with dementia;
- There will be over a million people with dementia by 2021; Two thirds of people with dementia are women;
- Dementia is most common in those aged over 60 and becomes more common with age;
- 60,000 deaths a year are directly attributable to dementia;
- The financial cost of dementia to the UK is around £23 billion a year;
- Two thirds of people with dementia live in the community while one third live in a care home; and
- There are 670,000 carers of people with dementia in the UK.

4.0 Dementia in Cheshire East

4.1 There are estimated to be 4,500 people living with Dementia in Cheshire East over the age of 65, of which 65% are likely to be women; one in five people over 80 has a form of Dementia and one in 20 people over 65 has a form of Dementia. Cheshire East has a higher than average older population and it is predicted that this will continue to rise in an upward trend; currently the population of Cheshire East comprises 17.8% of over 65 year olds compared to the national average of 15.9%. As the older age group increases in size so the numbers of people with Dementia is also likely to rise. The number of people aged over 50 with dementia in Cheshire East is anticipated to be

around 9100 in 2030.

- 4.2** Although Dementia is predominately a disease affecting people over 65, there are still a number of people with Dementia in the under 64 age group; with data for Cheshire East suggesting that there are 65 people aged 55 – 64 with Dementia; 9 people aged 45 – 55; 6 people aged 30 – 44 and 4 people aged 18 – 29. The vast majority of people in Cheshire East with Dementia are White British (97%). People with Dementia are living in all areas of Cheshire East in fairly equal numbers.
(source: Joint Commissioning Plan Dementia – CEC and CECPCCT and Ageing Well in Cheshire East Programme)

5.0 Awareness and Diagnosis of Dementia

- 5.1** As people are living longer, and the proportion of older people in Cheshire East continues to rise in an upward trend, it is going to become increasingly important to ensure that there is good awareness of dementia. Improving awareness of dementia is Objective 1 of the National Dementia Strategy. If there is good awareness of dementia this will help to ensure that people seek help and support at an early stage and will enable both services and individuals to be prepared.
- 5.2** As soon as dementia is diagnosed, the person concerned and their family can begin interventions and make longer term plans. However, the majority of people with dementia do not receive a diagnosis. A recent study by the Alzheimer's Society, found that 65% of GPs say people with dementia are not diagnosed because they do not make an appointment to see their doctor. Locally, again according to the Alzheimer's Society, 44.2% of people in the Central and Eastern Cheshire Primary Care Trust (PCT) patch in 2011 had received a diagnosis of dementia, representing 2,800 people. This is in comparison with 6337 people in the same year who are estimated to have dementia.
- 5.3** There needs to be both general awareness of dementia and its symptoms, as well as awareness among professionals who may come into contact with people who may develop the disease. Early diagnosis means people can begin to get support and treatment as well as beginning to make plans for their future. It is important that there is an understanding about the type of symptoms to look out for and what to do if you suspect you or someone close to you may be developing dementia. It is important that this information is widely available. The Alzheimer's Society conducted a survey of 382 GPs as part of a campaign "Worried about your memory?" whereby leaflets were produced and sent to GP practices to encourage people to contact their doctor and speak to the Alzheimer's Society if they had any concerns. This is a useful initiative; the Group is aware that the Alzheimer's Society leaflets are available in local GP practices and commends this and recommends the leaflets should be widely available. Carers, to whom the Group spoke, felt that there was a lack of awareness among the general population and more should be done to raise awareness of the illness.

- 5.4** Understanding the extent of dementia in the area can be helped through having a dementia register. Dementia registers are held in primary care at general practice level. Having such a register is a key feature of the Quality and Outcomes Framework. The Group has been unable to ascertain a clear picture regarding the holding of dementia registers and recommends that this is investigated further by the Scrutiny Committee.

6.0 Demenshare

- 6.1** During the course of the review an initiative - Demenshare (www.demenshare.com) - was piloted in Cheshire East through a partnership of Cheshire East Council, Age UK Cheshire, Central and Eastern Cheshire Primary Care Trust, Alzheimer's Society and / Zero a small social enterprise. Demenshare is an online social media resource that enables people affected by dementia across Cheshire East to share and exchange their experiences and knowledge with other people. The site provides information about dementia, useful links, online groups and individual stories. Currently there is a blog (online diary) written by a man whose wife has dementia, detailing the family's recent trip to America; as well as providing a wealth of information on how to prepare for such a trip, it is an inspiring account of living well with dementia.. At July 2012, 443 were people registered with the site and there had been 10,612 "hits"; the site has been accessed from 88 countries and read in 38 languages. There have been a number of referrals to the site from GPs and at least 3 crises have been averted. There have been 6,935 visitors to the site, 708 followers on Twitter, where good feedback has been received, and 91 "likes" on Facebook.

- 6.2** The Group commends the site as very useful for raising awareness of dementia and as an additional way of providing support and information. As more and more people use the internet and are comfortable with social media, this will be an increasing popular means of communicating and a way of obtaining information and support. With the increase in technology and increasing use of smart phones it means people can access such applications in many environments. This will be an increasingly common way of accessing information for present and future generations. The Group hopes that Demenshare.com is promoted by GPs, health professionals, social care staff and voluntary groups as widely as possible. The Group is aware that funding is not secure for the website and urges commissioners to consider how this vital resource is retained. The Group has also heard that there is a lack of awareness among a number of GP practices about Demenshare and recommends that the site should be promoted directly to GP practices.

7.0 Dementia Kitemark

- 7.1** The Group received information about the development of a "dementia kitemark" - through this scheme small businesses (such as hairdressers and local shops) will receive training in dementia awareness, safeguarding and mental health and will be able to display a "kitemark" sign to demonstrate their awareness and that they have had training to assist people with dementia. At February 2011 Dementia training had been delivered to 650 people in

Cheshire East and was in the process of being rolled out to GP practices and leisure centre staff. This is seen as an important development in raising awareness of dementia and helping to support people living with dementia to carry out normal activities in their community. The Group commends this initiative and urges that training is rolled out to as many areas as possible to ensure that the kitemark is displayed as widely as possible.

8.0 Diagnosis

8.1 The Group is aware that dementia is difficult to diagnose and that symptoms may be due to other reasons, such as depression. However, it is important to get a formal assessment so that other causes of symptoms are ruled out; a referral to appropriate services can be made; and the person and their family can begin to make plans for the future. It is also important to get a diagnosis because certain forms of dementia can be treated with drugs.

8.2 The Group met with a GP who outlined that discussions were underway regarding the screening tool to be used in diagnosing dementia. Carers, to whom the Group spoke, felt that from their experience dementia was a difficult illness to diagnose. One solution they suggested would be to have a separate surgery with longer appointment times and specialist doctors, but even then dementia would be difficult to detect. The local GP reassured the Group that GPs were willing to make specific appointments for patients who were showing signs of memory loss to enable a proper assessment to begin rather than it being dealt with alongside other health needs in a ten minute appointment or if the had person raised it briefly at the end of a consultation. The Group was pleased to hear that GPs would assess patients by visiting them in their own homes thereby seeing them in their own environment in which they feel comfortable and familiar. If required, further tests and assessments would be conducted with consultants. However, the Group also heard that there was some reluctance among some GPs to diagnose dementia because of a perceived lack of services and support (check with Andy Wilson). The Group is concerned to hear this as it is important that diagnosis is made at an early stage to enable plans and support to be put into place; indeed, the Group heard from a lady at a Dementia Café that she was relieved to have received an early diagnosis for the very reason that it meant she could make plans with her husband in preparation for her future needs. The Group was advised that the Clinical Commissioning Group would be adopting a holistic approach rather than seeing dementia as a separate issue. This is seen as a very important principle whereby support is built around the patient rather than the patient accessing different services depending on their needs. The Group feels that training in dementia is very important, particularly in primary care, and seeks reassurances that training in this area is seen as a priority.

8.3 The Group heard evidence about how dementia is diagnosed. Currently, a person under the age of 65 would be referred to Adult Services; anyone over 65 would be referred to Older People's Services. It was planned that in the future, people with dementia would received support from dementia specialists regardless of their age, this would be through SMART teams.

SMART teams (Skilled Multi Agency Response Teams) comprise social care workers, occupational therapists, district nurses and community matrons and are aligned with GP practices. The Group supports the introduction of SMART teams as this joint working between social care and health will help to ensure continuity of care for the patient and carer and can help in forming constructive relationships with those responsible for providing services and support.

9.0 Memory Services

- 9.1** The Group has heard that GPs are generally happy with the current provision of memory services but more work is needed around capacity issues and ensuring services link together in a consistent pathway. (T Ault's update to Group June 12). Funding secured via the Department of Health and available for Councils to use for memory services will be spent this year on Dementia Advisers; in subsequent years this will be funded from grant funding from Clinical Commissioning Groups. The Dementia Advisor service is being developed in collaboration with the Alzheimer's Society, Age UK and the Fire and Rescue Service. The Group welcomes the availability of funding for this important role and the partnership approach to delivery. The provision of Dementia Advisers means that help and support can be provided to a person and their family upon diagnosis and throughout their care through one named person. The Group commends this new role and hopes that funding should be made available from the Clinical Commissioning Groups from 2013 for this important role.

10.0 Current Provision in Cheshire East

- 10.1** Services for people with dementia vary from nursing and residential care to respite and day care, as well as services in the home and community that play a support and preventative role. The Authority does not provide any residential provision but the Group has heard that there is sufficient provision in the private sector from a wide range of providers and this topic has been addressed in the Scrutiny Review of Residential Provision.
- 10.2** The Authority does provide day care services, respite and short breaks, reablement and support to people to remain in their own home through either managed services with domiciliary agencies or through the provision of a personal budget.
- 10.3** There have been a number of developments in Cheshire East Council since it came into existence in 2009 including a building based review. Services are currently provided at -
Day Service:
- Redesmere, Handforth;
 - Brocklehurst Unit, on the Hollins View site, Macclesfield;
 - Salinae, Middlewich; and
 - The Hilary Centre, Crewe.

Respite and Short Breaks:

- Lincoln House, Crewe –12 bedded specialist dementia unit;
- Hollins View, Macclesfield; and
- Mountview, Congleton.

There are also a range of services provided by community and voluntary groups including Age UK and Wishing Well.

- 10.4** The Group is concerned that there is limited amount of fit for purpose respite provided by Cheshire East, especially in the light of the growing demand through the increasing older population in the Borough. However, the Group was further advised that there is little take up of local authority respite with private respite being used to a greater extent. The Council has recently made arrangements through contracts with St Luke's Hospice and East Cheshire Hospice, to provide a range of dementia services including respite where care can be provided at home. There is a social care review currently underway – Baseline Assessment Review – to ascertain views of service users on what facilities and services they have used and what their thoughts are on those facilities.
- 10.5** Members of the Group have undertaken visits to various existing Local Authority provision in Cheshire East including Lincoln House, Lindow Day Service (which is now provided at Redesmere) and Mountview and generally found the care provision to be of a good standard, well managed, with a good range of activities and a pleasant environment. However, there is concern that the provision at Mountview suffers from a lack of en-suite rooms especially adjacent to the secure day rooms. A visit to Lincoln House, Crewe, on the other hand, enabled the Group to experience a well designed building whereby the needs of people with dementia were fully incorporated in the design of the building. There was secure outdoor space available to residents and day care customers. Members noted and observed the wide ranging number of activities and the facilities available, such as hairdressing, as well as having the opportunity to speak to those attending the Centre. Members felt this was provision that should be replicated in the north of the Borough. On a visit to another facility a Member observed that the growing uptake of services by dementia patients meant increased pressure on existing staff and resources which was an issue that would need to be addressed as dementia cases continue to rise.
- 10.6** A number of facilities have been inspected by Cheshire East Local Involvement Network using their Enter and View powers. For the most part, their inspections were positive and commended many of the features, services and staff e.g. "we were impressed by the simple and discreet method of identifying the support needs of clients" and "satisfaction with the Centre was high".
- 11.0 Enabling People to remain in their own home**
- 11.1** For many people it is important to remain living at home for as long as possible. People want to remain in a familiar environment and keep their independence. This was one of the findings from the Wanless Social Care

Review “Securing Good Care for Older People” - when questioned about their preferences should they need care, 62% of people indicated they would like to remain in their own home with care and support from friends and family. And 56% indicated they would like to remain in their own home with care and support from trained care workers. As people grow older they are more likely to need help with health and personal care in order to remain at home. This care may be provided by family and friends but others may need help from social care, the NHS or from voluntary organisations. Older people are the biggest group of people receiving care but also the biggest group of carers (source: Ageing Well in Cheshire East programme). To enable people to remain living at home, services must reflect and support this aim. For someone with dementia, support is needed both for themselves and for their carer, if they have one.

- 11.2** This support can be provided in a number of ways – directly through the use of Assistive Technology; the Direct Payments/personalisation approach and by supporting the carer of the person with dementia.

12.0 Assistive Technology

- 12.1** The provision of Assistive Technology can support people at home as well as providing some peace of mind for family and carers. As well as meeting people’s needs and enabling them to remain in their own home for longer, the use of technology at home is a more economical option than residential care. Assistive Technology has a preventative role by raising the level at which people need physical support from others.

- 12.2** The Group heard about various types and roles of Assistive Technology including:

- Wrist or Neck Pendant – which would send an alarm to the contact centre who would respond;
- Pull cord – which would send an alarm to the contact centre who would respond;
- Movement sensors – these would detect if there had been no movement within a set time period possibly indicating a fall or illness;
- Pressure sensors – these would detect when a person got out of bed/armchair and then back again, based on preset times and may indicate a fall;
- Medication dispensers – automatically prompting people to take medication at a preset time;
- Front door sensors – to detect when a door was opened and someone had left the property;
- Alerts that would detect smoke or a rapid rise in temperature or carbon monoxide or water on the floor;
- Fall detector – automatically sensing that someone has fallen;
- Bogus caller button – enabling people to discreetly contact help if they are suspicious about a caller at the door.

- 12.3** Many of the above features can send an alert to a call centre or to a carer. This includes sending an alert to a carer in a different part of the house which can enable a family carer to get some rest even if their loved one is awake and up during the night.
- 12.4** The equipment, including installation and maintenance, is free with a small charge to link to the call centre (which the Group understands may be reduced as it is an assessed charge).
- 12.5** Other initiatives include the Just Checking system which can assist people with dementia to live independently in their own home by monitoring their movements at home and generating a chart of activity, on-line. Care professionals use the system for assessment and planning care. Just Checking highlights what a person is able to do for themselves in the familiarity of their own home, and the effect of care services. Families use it to 'just check' that a family member is following their usual pattern of life, without intruding or undermining their independence. It is simple to install and provided at no cost to the customer.
- 12.6** Members of the Group undertook a visit to a demonstration flat to view various types of Assistive Technology for themselves. They were shown how the technology works and were given a demonstration of how an alert would be sent to the call centre. Members noted the unobtrusive nature of much of the technology and the ease of use. The Group was impressed by the wide ranging and effective types of technology available which were also economical to install and manage for both the user and the Authority.
- 12.7** The Group has been advised that demonstrations of assistive technology will soon be available at Independent Living Centres in Wilmslow and Crewe. These simple products can have a big impact on people's lives through helping people stay at home for longer as well as providing reassurance to families and carers. It is important that these various sources of help are promoted as widely as possible and that people understand that they can access such help themselves without having to go through social care. It is also important for people to investigate what assistance is available at an early stage to ensure support is in place and deterioration into more intensive and expensive services can be delayed. This emphasises the importance of getting diagnosed at an early stage so support can be identified and trialled and people can get used to how they can use it to benefit themselves and their families. The Group understands that it is possible for some people with critical and substantial needs to remain at home with the help of Assistive technology and respite. As well as enabling people to maintain independence and the familiarity of their own environment it is less expensive than a residential placement. It can provide peace of mind for the family; and the use of technology to send an alert to a family member within the same house enables them to rest without worrying unduly about their loved one.

13.0 Direct payments/personalisation

- 13.1** A further way of supporting people to remain at home is through Direct payments/personalisation. Direct payments are cash payments made to people who have been assessed as needing help from Social Care to help them to live at home. Instead of Social Workers arranging services, people can choose to arrange their own services using their direct payment. This enables people to exercise choice and is ideal for people who like more independence and control over how the support they require is arranged and who are able to manage the payments on their own or with help from another person.

14.0 Carers

- 14.1** Carers undertake a vital role in supporting people with dementia and enabling them to remain at home for as long as possible by providing day to day support. It is therefore important that carers themselves receive support. Support can be provided through the voluntary sector, through respite provision and through the undertaking of a Carers Assessment.
- 14.2** The Group spoke to representatives of the Alzheimer's Society, Crossroads Care and directly to some carers.
- 14.3** The Alzheimer's Society provides services for anyone with dementia and has trained Dementia Support Workers. These Workers assess the needs of the patient and their carer through a free and confidential service without the need for a formal diagnosis of dementia. Support is tailored to the needs of the individual and can include emotional support as well as practical services.
- 14.4** A Caring and Coping Course was run by the Society comprising 8 sessions. This course was for carers and included specialist speakers and peer support. The course was limited to a maximum of 12 people and included attendance by a hospital consultant and a solicitor. The course was run at different venues to ensure as wide access as possible; the Alzheimer's Society also has a contract with Crossroads Care so as to ensure that carers can attend the course.
- 14.5** The Society provides Lunch Clubs and runs Dementia Cafes. Members of the Group attended a Dementia Café held at a Garden Centre and spoke to dementia patients and carers. The café was well attended by both people with dementia and their carers. A Dementia Support Worker attended to give advice as needed and various written resources were available too. From speaking with those present it was clear people really valued the opportunity to meet with others undergoing similar experiences as well as enjoying the social aspect of meeting for a cup of tea in a nice environment.
- 14.6** The Group heard evidence from Crossroads Care which provides care for carers. Support is offered to carers of any age and includes advice and information, but most often involves practical support. People can self refer or be referred by a professional. A Care Assessment would be carried out and

would lead to a Care Plan – taking into account the needs of both the carer and cared for person. A Carer Break - a 3 hour break per week - would be offered which is free at the point of delivery. Domiciliary care is also available as a chargeable service. There are also other Groups who provide services to carers but again these are at a cost.

- 14.7** Crossroads Care offers a full range of services including bereavement support, support for young carers, support groups, palliative care and carer breaks. The organisation has been commissioned by the Council to provide emergency responses for carers.
- 14.8** The Group interviewed some carers and asked their views on early diagnosis, respite care and the charging and transport policy. Some carers were concerned that external carers (provided through a carers agency) did not spend enough time with family members and did not like that different carers attended each day which resulted in difficulties in building up relationships and understanding individual's needs. There appeared to be communication issues too as the external carers did not report back to the family as to whether they had been able to help the person wash or bathe or whether he/she had eaten. There also appeared to be a lack of consistency around care packages. One family carer would have welcomed training and information as she did not realise that Occupational Therapy Assessments and grants were available for home improvements, such as walk in showers.
- 14.9** The day care centres were seen as essential support to enable carers to carry out home care for their family member. There was a wish to see the centres also open at weekends as there was no alternative respite care available at weekends. A private 'Better Minds' day care centre was available, which would also provide care at home, however this was expensive.
- 14.10** The Police Community Support Officers were seen as carrying out an important role, as they made older people feel safe and were a regular point of contact.
- 14.11** The Group is aware that the Council has a Carers Strategy and Implementation Plan and this has been recently considered in some detail by the Adult Social Care Scrutiny Committee. It is clear that there is strong commitment by the Council to ensure carers' needs are taken into account and supported. The Scrutiny Committee was also made aware that there was ongoing work to help Clinical Commissioning Groups to develop joint commissioning intentions to support carers and that Carers' Leads had been identified within GP practices. This is to be commended. The Scrutiny Committee was also advised that the percentage of Carers' Needs Assessments carried out in 2011/12 was around 35.6% which is above the National Indicator target of 28%. However, social care teams are working hard to increase this figure as well as improving the quality of Assessments. One interesting conclusion which the Scrutiny Committee made was around awareness of services available to carers; it was felt that there were services available both from the Council and partners but these were not publicised to the maximum extent – the Scrutiny Committee recommended that a marketing

and communications strategy be explored to promote these services.

- 14.12** There has also recently been a comprehensive review of Carers Respite through a research project commissioned by the LINK and produced by Making Space. The Review report concludes that carers are not always clear how to access their Assessments and Care Plans and some carers are unclear as to whether or not they are eligible for one or even if they have had one. The Making Space report makes a number of recommendations in relation to Carer Assessments and provision of respite.

15.0 Transport

- 15.1** The issue of transport is an important one and has been considered in some detail in the Scrutiny Review of Residential Provision Task/Finish Group so is not addressed by this Review. However, one issue was highlighted by patients and carers at the Dementia Café, as they did not have their own private transport arrangements. A community transport service did transport people to the café but they were dropped off at 9.30 am and then collected at 11.30 am whereas the cafe ran from 10.00 am – 12 noon. This difficulty with transport services was reiterated at a further meeting of the Group when carers expressed the view that the timings of the transport available were wrong and journeys were too long.
- 15.2** Supporting people to remain in their own homes is important. People want to remain in familiar surroundings for as long as they can and therefore it is important to focus on preventative measures to support this desire. People's health and well-being can be maintained for longer if they remain in their own homes or in the community rather than in some form of residential care. Assistive technology has an important role in this respect – there is a wide ranging amount of technological help, most of which is quick and easy and economical to install. People can access assistive technology without needing a social care assessment; therefore good information and promotion to signpost them to this help is very important so people can make informed choices and access good value support.
- 15.3** There is a vital role to support carers and the Group commends the findings of the Making Space report. It would like to be assured that the conclusions and recommendations are acted upon and urges the Scrutiny Committee to review the report and consider what action has been taken since its publication. It also recommends that the Scrutiny Committee receives regular updates on the Council's Carers Strategy and Implementation Plan.
- 15.4** The Group knows that support for carers is essential. It enables them to continue supporting their family member in their home environment which is best for the dementia sufferer in terms of their quality of life and slower deterioration. In addition it means they are less likely to require expensive services or financial support from the Local Authority. As Kate from Crossroads Care explained to the Group - carers are the cheap option!

16.0 Spending time in Hospital

- 16.1** Someone with dementia may need to spend time in hospital as a result of their dementia or for unrelated reasons. The Joint Commissioning Plan Dementia 2012 – 2013 includes recommendations to improve services in general hospitals and improve access and treatment in Accident and Emergency. The importance of dementia awareness has been brought to the Group's attention in relation to the triage stage. Staff in A and E need awareness of dementia especially when a patient is an older person and may be waiting to be seen without a relative or carer.
- 16.2** The Group visited Ward 18, Leighton Hospital which was an elderly care ward to see what kind of care was available to patients including those with dementia.
- 16.3** The Group heard that on admission to the ward, a comprehensive process was followed to ascertain information about the patient including completion of a form "Information about me to help you" which contained information about personal care needs, routines, eating and drinking needs and likes/dislikes as well as information about the person as an individual. This ensured that if a patient needed help with eating they would be put on the red plate scheme. Also, on admission an abbreviated mental status test was carried out using a nationally recognised tool. The Group was pleased to note that protected meal times were in operation and there was a volunteer feeding scheme as well to provide assistance with feeding. This arrangement accords with one of the recommendations of the Joint Commissioning Plan. Hot drinks were provided on a two hourly basis throughout the day and pictorial menus were used.
- 16.4** The Group observed that there were four side rooms available. The Ward environment utilised colour coding to assist patients with finding their way round. The hospital also used assistive technology such as movement sensors to support patients. An activity lounge contained a reminiscence area and interactive sessions were held. A recent initiative had included attendance by the Royal Northern College of Music who had performed unobtrusively in the background of the ward and this had been extremely well received; this was an approach commended by the Alzheimer's Society in their document "Singing for the Brain" which demonstrated the positive impact of music for people with dementia.
- 16.5** There appeared to be good clinical support and leadership on the ward. There was a named senior clinician with responsibility for patients with dementia and regular ward rounds by consultants took place. Hospital psychiatric services were now available 24 hours a day with most referrals responded to in accordance with emergency or urgent response time standards. The Community Psychiatric Nurse was welcome on the ward and the Alzheimer's Society attended regularly. The Group welcomed the role of the Integrated Discharge Team which included Hospital Trust and Local Authority staff with a specific role of Dementia Sister. The Group heard that this Team had had a positive impact and was liked by the ward staff who felt it

helped with continuity and transition. The ward would contact the Team once a patient was admitted so that discharge arrangements could begin to be considered as it was recognised that patients should be returned to their familiar environment as soon as possible.

- 16.6** The Group was pleased to hear that staff received mandatory training on dementia through various methods including through the Dementia Link Nurse. Dementia Care Guidelines were available on the hospital intranet. Staff had commented that they would like to receive more training and that there were practical difficulties in organising training due to the 12 hour shift patterns which did not allow for crossover times at shift changes. The Hospital Dementia Care Pathway Audit had identified the provision of education to ward staff about the Pathway as an action for the Dementia Nurses to undertake. The Group heard that 2 study days had been held at Cheshire Hospices' Education that had looked at end of life care and dementia for both palliative and dementia link nurses; these days were extremely well attended and evaluated. The Abbey pain tool was available to download from the Dementia Care Guidelines to assess pain in people with dementia who could not verbalise their needs. There were also excellent links to, and support from, the Hospital Macmillan Nurses and the Hospice.
- 16.7** The Group appreciated the welcome they received by staff on Ward 18 at Leighton Hospital and all the good work and initiatives to help older people on the ward.
- 16.8** The Group has also received some information from East Cheshire Hospital Trust who outlined that there was to be the creation of a 22 bed Elderly Care Unit with a specific focus on dementia including an assessment area for frail elderly patients such as those with dementia. The environment would be dementia friendly and red trays and protected meal times were to be introduced including volunteer helpers. There has been a focus on staff training with almost 80% of clinical staff having had dementia awareness training to date, 951 staff have completed a Dignity Work Book and an Admiral Nurse was in post one day a week to offer specialist advice, bespoke training and attendance at the Dementia Steering Group. The Trust followed the national Dementia Strategy and had joined the Dementia Improvement Community to audit and share best practice. The hospital also used "Forget-me-not" stickers to identify patients with dementia to the staff.
- 16.9** There is evidence of good practice at both Acute Hospitals and it appears that dementia training is a priority.
- 17.0 Extra Care Housing**
- 17.1** There is a variety of Extra Care Housing provision in existence in Cheshire East through various schemes some of which the Council has block contracts with (Registered Providers) and some that is solely private provision. Key features of the provision include a safe and secure garden area and communal areas including restaurant and gym facilities. There is also 24 hour support providing personal care, basic health care and support with activities

and practical tasks depending on level of need. The scheme utilises technology to provide added security. The schemes are suitable for people with differing needs resulting in a mixed community. The Extra Care Housing Project in Cheshire East aims to provide a number of additional homes in Poynton and Sandbach by 2014.

- 17.2** Extra Care Housing can be an alternative to residential or nursing care because it provides support in an individual's home, in a purpose built complex, through a range of on-site services and therefore can help prevent people's deterioration into more intensive and costly services. It enables people to live in a home environment rather than an institutional setting but with a good range of health and social care support available. There are activities available both social and active (such as a gym and exercise classes) to maintain mental wellbeing and physical fitness as well as restaurant facilities if people don't want to cater for themselves on occasion.
- 17.3** Members of the Group visited the provision at Willowmere in Middlewich; this development has apartments which can be bought (outright or through shared ownership) or rented, with the additional payment of a service charge. Apartments are spacious, mostly wheelchair accessible, with specifically designed shower rooms and ample space on the main corridors to park mobility scooters. There were various activities on offer, a gym and café. Members were told that personal care and practical support is available and a care manager will meet with residents to draw up a care plan. Although the Group note that this provision is expensive it is considered more appropriate for people with dementia.
- 17.4** This issue has also been looked at by the Scrutiny Review of Residential Provision who visited Beechmere in Crewe. That Group noted that there were a number of residents at Beechmere with particularly complex needs due to dementia and since residing there, their condition had improved. It was also commendable to note that there were relatively few referrals onto nursing homes as Beechmere staff were able to deal with all needs. That Scrutiny Group supported the Extra Care Housing approach although felt that a suitable mix of residents needs (low, medium and high) was not always achieved, and therefore financial savings were not always met. Also that Group felt that the schemes were often located in out of town situations which could prove isolating and did not promote integration into the community. That Group felt that such schemes need to be embedded in the local community, affordable and small enough to be personal. This Group echoes this view although the facility which it visited at Willowmere, did appear to interact well with the local community and was located in the middle of a residential area therefore did not appear isolated.
- 17.5** Members support Extra Care Housing provision, taking into account the findings of the Residential Provision Review as well. This type of provision enables people to remain independent but with support systems in place based on individual need. The environment is extremely pleasant and a wide range of activities are on offer. As the older population increases some form of supported housing provision will continue to need to be offered. The Group

endorses the findings of the Residential Provision Scrutiny Task/Finish Group and recommends that appropriate supported housing provision will continue to be provided to meet the growing older population.

18.0 The role of the Voluntary sector

- 18.1** There is an important role for the voluntary sector in helping older people and people with dementia. The Group heard evidence from Age UK, the Alzheimer's Society and Crossroads Care.
- 18.2** Age UK Cheshire provides a diverse range of care and support services to promote the well being of all older people in Cheshire. Services on offer include advocacy, day services, Fit as a Fiddle (helping older people to remain active), Men in Sheds (for older men who feel isolated or are experiencing major life changes), mentoring (a free, confidential and impartial support to people over 65 who are finding it hard to manage their personal finances). There are a number of day centres available for people with dementia; Age UK has worked in partnership with the Council in the provision of the Dementia Advisor service and the Demenshare website.
- 18.3** The Alzheimer's Society explained that due to an increase in people being diagnosed with dementia at an earlier age, a reassessment of the services available was underway. An Early Onset Project had been introduced to reflect this increase including developing social activities and a dementia café specifically for a younger age group.
- 18.4** Financing was a concern as less than half of the services provided by the Alzheimer's Society were funded meaning the remainder needed to be raised through local fund raising. To date the service had never turned people away but was working to capacity. The national organisation tended to concentrate on research, campaigns and backroom support; money spent locally was raised locally. As numbers of people with dementia continue to rise the demand for the services of the Alzheimer's Society would inevitably grow.
- 18.5** In relation to diagnosing the disease, a view expressed was that early diagnosis would only be of assistance if the relevant drugs were available to help. NICE was currently campaigning for a drug to be reinstated that had fewer side effects. It was felt that there was still a stigma around the disease leading to people trying to cover up their symptoms and it was not unusual for partners of sufferers to play down the severity of the problems resulting from dementia. It was explained that this could make assessments difficult. In speaking to Carers the Group was told that assessments took too long to be carried out leading to delays in receiving a care package. They also felt that there were not consistent discharge procedures to discharge dementia patients from hospital.

19.0 Costs of dementia

- 19.1** At the start of the Review, the Group received figures on the numbers and cost of care for people with dementia in Cheshire East - 418 people

diagnosed with dementia in Cheshire East received a direct payment/individual budget; 383 people diagnosed with dementia received day care and 684 people had been diagnosed with dementia and were in residential or nursing care. The Group sought information on the numbers of people who had previously been able to afford the cost of their own care but were then having to turn to the Authority for financial support. The Group was advised that at December 2010, 92 people diagnosed with dementia were now having their care paid for by the Council (having been previously self funding) and this was at a cost of £2.3 m - £25000 per person; it was likely that this situation would increase with more people having to call on the resources of the Authority to support them in their care.

19.2 Information from the Joint Strategic Needs Assessment notes the accelerating costs of dementia care as need for more intensive services increases:

- People in the community with mild dementia - £14,540 per year;
- People in the community with moderate dementia - £20,355 per year;
- People in the community with severe dementia - £28,527 per year;
- People in care homes - £31,267.

19.3 This is clearly of concern as these costs can only rise as increasing numbers of people are diagnosed with dementia. It is essential that services are cost effective and that finance is targeted at prevention to improve people's quality of life and prevent for as long as possible, deterioration into more extensive and expensive services.

19.4 The issue of self funder migration has been fully explored in the Residential Provision Scrutiny Review and a number of suggestions made as to how this complex issue could be addressed. This Group endorses their findings.

20.0 Preparing for the future

20.1 Members discussed the importance of helping older people to put their affairs in order and were advised about the Living Wishes scheme – this was a list of wishes that included sorting out a will, arranging Power of Attorney etc, from which the person would chose 10 – 15 that would build up their own Care Programme. This approach is commended as a proactive way of getting people to think about the future and their potential needs and wishes.

21.0 Conclusions

- 21.1** Dementia is a major issue that affects an increasing number of individuals. As well as the personal cost of suffering and deterioration affecting individuals and their families, there is a financial cost too. Awareness of dementia is vital so that people can look out for the signs and symptoms at an early stage and start to make any necessary preparations. People's outcomes are better if they can be cared for in their own familiar environment and remain with people they know and care about. Therefore, preventative and supportive facilities are vital. Support to carers is essential as, without carers providing vital support at little or no cost, the Authority and voluntary sector would need to fill in the gaps in provision, which would be more costly and less helpful for the individual dementia sufferer.
- 21.2** The Group commends the services it has visited – day centres, Dementia Café, Community Support Centres, Acute Hospital. The voluntary sector has an important role in supporting individuals and their families but must have sufficient support to continue its vital role.
- 21.3** The cost of dementia is of great concern particularly with the increase in the older population in Cheshire East. It is vital that preventative services are available and widely known about, particularly when they are relatively inexpensive and easy to install, such as Assistive Technology. It is also important that people get good guidance about managing their finances to enable them to get the best use of their money for as long as possible, should the need arise. Information about dementia is important so as to enable forward planning of services and provision and in this regard work must be undertaken with GPs through the Clinical Commissioning Groups to get a useful picture.
- 21.4** As this Scrutiny Review progressed, the Joint Commissioning Plan was published and latterly, the Ageing Well in Cheshire Programme – a plan for people aged 50 and over. These are both important initiatives and it is recommended that the Scrutiny Committee reviews both on a regular basis.
- 21.5** Although there are many challenges as the population ages and dementia cases rise, there has been a great deal of good work and many good services which is to be commended and encouraged.

22.0 Recommendations:

- (1) That all opportunities to raise awareness of dementia be developed both by the Council and partners including wide distribution of the “Worried about your Memory?” leaflet produced by the Alzheimer’s Society, resourcing and promotion of the Demenshare website and introduction of the dementia kitemark;
- (2) That integrated working is encouraged and supported through the use of SMART teams and joint working with the Acute providers such as the Integrated Discharge Team, Leighton Hospital. In this respect the Scrutiny Committee should review the effectiveness of the Joint Commissioning Plan Dementia 2010 – 2013;
- (3) That the Health and Wellbeing Board work with partners to improve levels of diagnosis of dementia;
- (4) That the role of Dementia Advisors be reviewed 12 months after implementation to assess their effectiveness and ensure adequate future funding is made available;
- (5) That preventative services are promoted widely, as they are often simple and cost effective ways of maintaining health and wellbeing and preventing deterioration into more extensive and costly services – for example Assistive Technology has an important role for both users and carers;
- (6) The Scrutiny Committee should regularly review the Carers Strategy and Implementation Plan as well as receiving an early report on action taken following the findings of the Carers Respite report produced by Making Space;
- (7) The Scrutiny Committee should receive and consider the outcomes of the Baseline Assessment Review of respite;
- (8) The Scrutiny Committee seeks assurances that Dementia Registers are held in primary care;
- (9) The specialist provision at Lincoln House, Crewe is commended and a similar facility should be provided in the north of the Borough and the facilities at Mountview should be upgraded;
- (10) The findings of the Residential Provision Scrutiny Review are taken into account, where relevant, when this Review is considered especially in relation to financial and transport issues; and
- (11) The outcomes of the Alzheimer’s Society pilot project ‘developing dementia friendly communities’, be evaluated as a potential for extension throughout Cheshire East. The towns in Cheshire East involved in the pilot scheme are Alsager and Knutsford.