Cheshire West
and Chester

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Dementia Strategy

2010-2014

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Executive summary

In the next ten years, the number of people with Dementia will grow significantly. In addition, the biggest growth in Dementia will be amongst the 'oldest old' – people with Dementia in their 80's and 90's with particularly complex needs compounded by a range of co-morbidities. This will put significant pressure on services that are already unable to respond effectively unless change is delivered.

(Alzheimer's Society, 2009, Dementia: what every commissioner needs to know)

The Joint Strategic Needs Assessment for Cheshire West and Chester (2007) estimated there were 4,000 people with Dementia (2007). This is set to rise steadily in the coming years. The Dementia population is expected to rise from 4,050 in 2008 to 6,517 in 2025. This is an increase of 61%. This will put an unprecedented strain on health and social care resources. These figures exclude the under 65's. Many family carers of people with Dementia are senior citizens and frail themselves, with mental or physical health needs. Dementia is a terminal condition but people can live with it for 7–12 years after diagnosis.

The National Dementia Strategy was published in February 2009 it aims to ensure that significant improvements are made to Dementia services across three key areas; improved awareness, earlier diagnosis and intervention and a higher quality of care. In response to this, a Baseline Assessment report was commissioned by NHS Western Cheshire and Central and Eastern Cheshire Primary Care Trust from Alzheimer's Society in the Autumn of 2008.

The newly formed Cheshire West and Chester Council, in conjunction with NHS Western Cheshire, agreed to engage with the Care Services Efficiency Delivery as an early adopter site to apply the methodology to evaluate the current system and identify an improved Dementia Care Pathway and ultimately inform the Dementia Strategy.

Engagement of main carers and people with Dementia is a core principle of the methodology. The following are quotes from carers in Cheshire West and Chester:

'The key is diagnosis, once there is a diagnosis, it opens everything up
and the services are then usually very good'
(Daughter supporting mother to care for her husband)

'Over 4 years we went to different GP's, my husband underwent many blood tests
and it was even suggested he was suffering from constipation.
We were not taken seriously for 3–4 years
Eventually we got him to a memory clinic and assessed'
(Female carer for Husband)

'Part of the treatment and care is helping the carers on how to handle sufferers,
especially as a support group.'
(Male Carer for wife.

'It is not only memory loss, but there are hallucinations and violence
which can become very pronounced.

My wife tried to attack me with a kitchen knife – so totally out of character.'
(Male Carer for wife).

This strategy considers the national context and its application to the local community of Cheshire West and Chester, using the Care Services Efficiency Delivery methodology to gain a better understanding of the care pathway and current quality. It considers the current financial commitment in services across Health and Social Care and identifies priorities for change, linking these to other relevant local strategies. The key outcome is the identification of a new model and sixteen key areas for implementation with draft new or revised service specifications.

1 Introduction and purpose

1.1 Rationale

The National Dementia Strategy was published by Department of Health in April 2009; it is a five year strategy which runs until 2014. The main purpose of this strategy is to respond to the national guidance and set out a clear direction and vision for the transformation of Dementia services in NHS Western Cheshire and Cheshire West and Chester Council localities. This document includes both the national and local context and identifies the strategic framework for high quality service delivery via partnership working across health, social care and the third sector.

1.2 Scope

The strategy aims to deliver services for everyone with Dementia and their families in the catchment's area.

1.3 Principles

The strategy will deliver services that are:

- Based around the needs of individuals and their families
- Are consistent with the evidence base, where this exists, or with National consensus guidelines
- Are integrated across health, social care and third sector
- Address health inequalities related to Dementia.

2 National context

The National Dementia Strategy identifies three key themes for Dementia support:

- Improving awareness; increased public and professional awareness of Dementia and an informed and effective workforce for people with Dementia.
- Early diagnosis and intervention; good quality early diagnosis and intervention for all as the rule rather than the exception; and achieve this by locating the responsibility for the diagnosis for mild and moderate Dementia in a specifically commissioned part of the system; good quality information for those with Dementia and their carers, including making the diagnosis well and delivering this sensitively and providing individuals with immediate treatment, care and peer and professional support as needed.
- Enable people with Dementia and their carers to live well with Dementia by the provision of good quality care for all with Dementia from diagnosis to the end of life, in the community, in hospitals and in care homes.

Dementia presents a huge challenge to society both now and increasingly in the future. There are currently 700,000 people in the UK with Dementia, of whom approximately 570,000 reside in England. Dementia is predominantly a disorder of later life but at least 15,000 people under the age of 65 have the illness. Its incidence and prevalence rise exponentially with age, and it affects men and women from all social and ethnic groups. Approximately 15,000 people from minority ethnic groups have some form of Dementia, but this number is set to rise sharply as their populations age. (The Alzheimer's Society report Dementia: '*What every Commissioner needs to know'* states that one in six people over 80 have a form of Dementia and one in fourteen people over 65 years has a form of Dementia).

Dementia costs the UK economy £17 billion per annum and in the next 30 years, the number of people with Dementia in the UK is estimated to double to 1.4 million, with the costs trebling in excess of £50 billion a year.

2.1 What is Dementia?

Dementia results in a progressive decline in multiple areas of function, including memory, reasoning, communication skills and the skills needed to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which complicate care and can occur at any stage of the illness. Dementia is a terminal condition but people can live with it for 7-12 years after diagnosis. The main sub types of Dementia are: Alzheimer's disease, vascular Dementia, mixtures of these two pathologies and rarer types such as Lewy body Dementia, Dementia in Parkinson's disease and frontal-temporal Dementia.

The Dementias all share the same devastating impact on those affected and their carers and can affect adults of working age as well as older adults.

People with learning disabilities are at particular risk.

For more detailed definition of the types of Dementia refer to Appendix 1 – as stated by the Alzheimer's Society.

2.2 Wider policy context

Given the prevalence of Dementia the individuals and their families are affected by the wider policy context. This currently includes initiatives, policies and guidance such as:

- Our NHS, Our Future, Putting People First: A shared vision and commitment to the transformation of adult social care including the future shape of the care and support system
- National Institute for Health and Clinical Excellence (NICE) commissioning guide on memory assessment services
- Carers Strategy and the National End of Life Care Strategy

2.3 National objectives

There are 17 key objectives in the National Strategy:

1) Improving public and professional awareness and understanding of Dementia and reduce the stigma associated with it.

   Promote timely diagnosis, prevention of Dementia and reduce social exclusion and discrimination.

2) Good –quality early diagnosis and intervention for all. The pathway of care should deliver competent assessment accurate diagnosis, treatment care and support as required to all new cases.

3) Good –quality information for those with diagnosed Dementia and their carers including information at diagnosis and throughout the pathway.

4) Enabling easy access to care, support and advice following diagnosis. A Dementia Advisor to facilitate easy access to appropriate care, support and advice for people with Dementia and their carers.

5) Development of structured peer support and learning networks, peer support for people with Dementia and their carers and active involvement in the development and prioritisation of local services.

6) Improved community personal support services including a range of flexible and reliable services such as early intervention, specialist home care delivered in a personalised manner to enable people living alone or with carers utilising personal budgets to remain in their own homes for as long as possible. This includes people who self fund.

7) Implementing the Carers' Strategy. Carers are the most important resource and have a right to an assessment of their own needs including identifying a support plan which could include good quality personalised breaks and recognise the needs of children in caring roles.

8) Improved quality of care for people with Dementia in general hospitals this includes leadership for Dementia, defining the care pathway and commissioning of specialist liaison older people's mental health teams to work in general hospitals.

9) Improved intermediate care for people with Dementia ensuring it is accessible and meets their needs.

10) Considering the potential for housing support, housing – related services and Telecare this includes engaging people with Dementia and their carers in developing housing options and assistive technology in order to prolong independent living.

11) Living well with Dementia in care homes, improving quality via strong leadership, defining a care pathway and commissioning specialist in-reach support from Community Mental Health Teams and inspection regimes.

12) Improved end of life care for people with Dementia, involvement in the planning as outlined in the Department of Health End of Life Care Strategy.

13) An informed and effective workforce across all sectors including effective basic training and continuous professional and vocational development.

14) A joint commissioning strategy for Dementia informed by the World Class Commissioning Guidance for Dementia.

15) Improved assessment and regulation of health and care services and of how systems are working for people with Dementia are their carers, this includes inspection regimes for care homes to better ensure the quality of care provided.

16) A clear picture of research evidence and needs

17) Effective national and regional support for implementation of the Strategy including information from evaluations and demonstrator sites.

3 Understanding the current local Dementia need

It has been difficult to obtain a detailed understanding of performance and expenditure within the current system. Within the timeframe available, the following data has been sourced:

The Joint Strategic Needs Assessment has highlighted the ageing population of Western Cheshire and associated health needs. It is estimated there are 4,000 people with Dementia (2007). This is set to rise steadily in the coming years. The Dementia population is expected to rise from 4,050 in 2008 to 6,517 in 2025. This is an increase of 61%. This will put an unprecedented strain on health and social care resources (this excludes people aged under 65 years)**.** See Appendix 2 for further breakdown by age band, gender and Area Programme Boards.

Appendix 3 shows the Dementia projections for Cheshire West and Chester for people aged 65 years and over by age band and gender.

For people under the age of 65 years, Dementia UK estimated that the number of people with Dementia in Cheshire was 188 in 2006. This comprised 111 men and 77 women.

The Alzheimer's Society guidance (2009), Dementia: what every commissioner needs to know estimates that in 2007 there were 2,911 people with Dementia in NHS Western Cheshire with a projected increase to 4,303 people by 2021, (47.8% increase). The number of people with Dementia on the GP Register April 2007 - March 2008 was 1,207 (only 41.5% of the total number of people with Dementia)

3.1 Baseline assessment report

The Alzheimer's Society was jointly commissioned by NHS Western Cheshire and Central and Eastern Primary Care Trust to produce a Baseline Assessment report of services for people with Dementia in Cheshire. The study produced both qualitative and quantitative information. Questionnaires were sent to health staff in both primary and secondary care and social care professionals.

Separate questionnaires were distributed to carers of people with dementia in order to collate their experience around diagnosis, access to information and support and any admissions to hospital. The Baseline Assessment included an analysis of the Quality and Outcomes Framework Data on numbers of people with Dementia on General Practice Dementia Registers. As of March 2009 there were 1,264 patients with Dementia (and a further 1,428 with symptoms but no diagnosis) figures of the amalgamated totals from 39 GP practices.

3.2 General Practice registers

Appendix 4 shows the Dementia count in Cheshire West and Chester source General Practice Registers, collated by town. 1,725 patients were identified. The numbers identified will be dependent on the age, gender profile of the local population outcomes are variable as each GP practice has interpreted the task differently and some may have been more rigorous in their analysis of their practice lists.

3.3 Information obtained from Social Care System (Client Record and Information Services System)

Appendix 5 shows age distribution of service users with Dementia who were in receipt of services from Cheshire West and Chester Council in 2008/09.

3.4 Activity in Secondary Care

Currently there are over 700 annual admissions to Countess of Chester Hospital of people with physical health needs who are also thought to have Dementia who attract an additional cost due to the complexity of their needs

4 Understanding the care pathway and current quality

A model developed by Care Service Efficiency Delivery had been piloted by Wirral Health and Social Care Services which could be applied to deliver an Integrated Care Pathway for Dementia. Locally it was agreed that NHS Western Cheshire and Cheshire West and Chester Council would become an early adopter site. This included ongoing support from Care Services Efficiency Delivery.

The Care Services Efficiency Delivery Model is based around five workshops which places the service user and carer at the centre of the process (see Appendix 6 for overview of the workshops). The model recommends 20% representation at the workshops of service users and carers. The aim of the Integrated Care and Support Pathway is to achieve efficiencies within the context of service transformation by focusing on service user outcomes to improve quality of life, create better choices and facilitate ‘right timing’ and ‘right servicing’. The methodology supports strategic commissioning for cost effective provision, assists credible budgeting and financial planning and examines inter-agency boundaries to assist collaborative working. Partnership working is at the core of the process.

The workshop process began on 9 September 2009 and concluded on 9 December 2009. The process entailed a detailed baseline mapping to produce an understanding of the current system including robust engagement with carers who provided personal accounts and commentary of their experiences. By workshop three, the strengths, weaknesses and gaps of the current system had been identified. Workshop four and five focused on identifying the components of the ideal pathway including drafting Service Specifications for revised or new services.

The research and analysis undertaken to support the process was considerable but necessary to collectively tease out the opportunities to achieve whole system redesign and sign up by all key stakeholders. The Project Team collated the ideas to form the new model and consulted with all Stakeholders. The final workshop prioritised the options applying the Risk Benefit Analysis approach.

4.1 Quality baseline mapping outputs – 'As is' (Appendix 7)

The chart shows the current 5 main entry points into the system: primary care, secondary care – mental health, secondary care – general hospital, third sector and social care. It highlights the complexity of the existing system and length of time that many carers can be left without support.

The National Audit Office in 2007 stated that nationally only about one third of people receive a formal diagnosis at any time in their illness. At a local level, an analysis of the Client Record and Information Services System in Cheshire West and Chester found that 1,175 service users in Western Cheshire had a diagnosis and 437 service users in Vale Royal had a diagnosis. A further 325 service users in Western Cheshire and 127 service users in Vale Royal had symptoms of Dementia but no diagnosis. A total in Cheshire West and Chester of 2,064 service users.

(The above has been collated from a search on Client Record and Information Services System and Care Notes of open interventions as at 01/04/09 that were marked as having Dementia (either based on the client's Primary Care Trust, on the Care Notes data received for Referrals, Assessments and Packages of Care Collection return, or with the words Dementia, wandering, or memory loss in the carer comments, Health behaviour, needs comments or relevant background other information free text field on the most recent Community Care Assessment screen).

The following table shows the number of Dementia service users by age group receiving services during April 2008 to March 2009:

	Total of service users	Community - based services in own home	Residential Care	Nursing Care
65+	976	656	237	261
18-64	19	18	1	1

Source – Cheshire West and Chester
Referrals, Assessments and Packages of Care Collection Full Year 2009.

Services available
An early element of the Care Services Efficiency Delivery process included identification of existing services. This was achieved using information from the Baseline Assessment Report and knowledge of the project team.
People with Dementia and their carers have general access to primary and secondary health care services. The General Practitioner is the main point of entry to this provision.

Teams providing services throughout Cheshire West and Chester include:

- Five patch teams and hospital teams at the Countess of Chester Hospital and Leighton addressing individual commissioning. Four Community Mental Health Teams deliver support to people with more complex needs which include people with organic and functional mental health diagnosis.
- The Memory Assessment Service managed by Cheshire and Wirral Partnership Trust provides individual consultations with the psychiatrist at Bowmere Hospital, Chester. Patients living in the Northwich/Winsford areas will attend Leighton Hospital.

There are a range of providers offering community support:

- Domiciliary support in house provider delivers a re-ablement service which is free at the point of delivery for between 2-6 weeks. This provides a further assessment period which identifies any residual Fair Access to Care eligible needs and informs the longer term Support Plan. There is a wide range of external providers whose primary role is to respond to the maintenance package of care.
- Cheshire West and Chester Council manage four Community Support Centres which offer a range of services. Sutton Beeches, Lightfoot Lodge and Leftwich Green offer intermediate care, respite beds and general day services and a limited specialist Dementia day service. Curzon House has been developed to provide specialist Dementia respite (18 beds) and a 20 place specialist day service.

In addition to the above, the PACT co-ordinate Family Based Care which supports people with mild to moderate Dementia in a homely environment. There are currently 160 people a week in receipt of the service, of whom 80% have memory problems. They also have extensive experience of delivering carers' courses and carers' support groups.

The Third Sector provides a range of support including information, advice, befriending, counselling, advocacy, Dementia café, carers' support groups, socialisation, training for professionals and low level day service. The three main providers are the Alzheimer's Society, Age Concern and Crossroads. See Appendix 8.

Extra Care Housing in Cheshire West and Chester area includes Hallwood Court in Neston (17 apartments and 3 respite beds), Callin Court in Chester (42 apartments) and Meadow Court in Frodsham (13 apartments).

In addition there are two new build private finance initiatives, Hollymere in Ellesmere Port (71 apartments) and Hazelmere in Winsford (106 apartments). Extra Care Housing is not exclusively for people with Dementia and offers varying levels of support to respond to the identified needs of an individual. These facilities offer communal and private lounges with secure garden areas. The individual apartments and front doors can be linked to a call system. Depending on the needs, staff can offer 24 hour support. A further development is planned for Northgate in Chester.

There is a range of residential and nursing home providers in the Cheshire West and Chester council area. There are 942 residential beds and 600 nursing beds of which 334 residential and 338 nursing beds are registered for the Elderly Mentally Ill.

4.2 Consultation undertaken by Alzheimer's Society as part of the baseline assessment

The National Strategy highlights the significance of service user and carer engagement in developing the Dementia Strategy prior to the workshops the Alzheimer's Society undertook research via three postal questionnaires. The first focussed on service providers in the voluntary or third sector to identify the range of provision. The second survey was targeted at Professionals to explore attitudes to Dementia including an audit of learning and development which also identified training needs. A total of 1,410 questionnaires were distributed with a response rate of 15%. The third survey was aimed at Carers of people with Dementia to better understand their experience of the Pathway. A total of 120 questionnaires where distributed with 63 returned (52.5%).

The more detailed information relating to the findings of these surveys refer to Appendix 8.

Key findings from the professional questionnaire include:

- The main challenge in their contact with people with Dementia is 'communication difficulties' followed by 'lack of time' and 'lack of training'.
- Many health professionals in allied health services and in acute hospital settings are concerned about the lack of information available on individual patients with Dementia. There are issues around sharing information between health and social services.
- 93% of professionals believe that people with symptoms of Dementia should go to their GP as the first port of call within services.
- 93% believe that a diagnosis helps the person and their family plan for the future.
- There is a general view that 'end of life care' for people with Dementia are not of a high quality. Over two thirds of professionals do not think acute wards provide high quality support for people with Dementia.
- 84% believe that people with Dementia would benefit from having a 'key worker' or contact person. Many think that access to services for people with Dementia without 'enduring' and 'severe' symptoms is limited.

- Two thirds of professionals have had no ‘Dementia related’ training in the last 12 months.
- The biggest gaps between training received and training desired was in ‘dealing with challenging behaviour’ and in ‘information and services to carer’s’ followed by ‘end of life’.
- Amongst this group of mixed discipline professionals 75% are unaware or unsure of any policies and procedures (or pathways) to follow for people with Dementia.
- The professionals surveyed think that ‘supporting the carer and family’ is the most effective way of improving the quality of life for people with Dementia. This is followed by having a ‘key worker’ and ‘clear Dementia pathways’ for people with Dementia.

Key findings from the questionnaire for carers:

- Carers believe that an early diagnosis is helpful and desirable.
- The time from symptoms being noticed to seeking initial primary care appointment is ‘within 2 years’ for 45% of people. This is less time than might be expected illustrating that the stigma of Dementia is breaking down.
- The length of time from initial GP visit through referral to confirmed diagnosis is still a significant problem (54% within 6 months but it still takes over a year for 31% of people). This is clearly more of an issue amongst younger people with Dementia and people with rarer forms or potential dual diagnosis i.e. with mental health issues.
- Within primary care/ GPs, issues still exist around what people with Dementia and their carers are told – such as ‘not much can be done’, ‘too young to have Dementia’ etc.
- The vast majority have good experiences at the time of diagnosis and are treated with ‘dignity and respect’. Thus by the time people are referred to specialist services, their experiences improve. Issues still exist around whether people with Dementia should be included in diagnosis consultations and how compatible this is with the emerging ‘mental capacity’ environment.
- 90% had received information and support as a carer, since the diagnosis of their relative. However, there is still some lack of information provision at diagnosis and later stages. Many people would also like this type of information earlier i.e. at GP’s.
- One third of people with Dementia had had a hospital experience - these were almost wholly negative with few exceptions – around attitude and training of staff, built environment and systems not being suitable rather than treatment received for physical complaint (often in specialist acute setting).
- Feelings of isolation exist strongly even with a better informed group such as those in the study.

- Peer groups still form an important role in supporting people with Dementia and particularly carers. There has been a move towards more participative ‘focus’ groups allowing people to get more involved and voice their views.

4.3 Consultation with service users and carers throughout the workshops

The Care Services Efficiency Delivery methodology recommended 20% representation by service users and carers for the workshop process. In Cheshire West and Chester we had one service user and 3 carers who consistently attended the five workshops.

In order to engage more effectively and to obtain a detailed baseline mapping to produce an understanding of the current system we invested time in between each workshop by engaging with existing carer’s groups as follows:

- Curzon House Carer’s Group
- Lightfoot Lodge Carer’s group
- Family Based Care
- Alzheimer’s Society Chester and Vale Royal service users and carers meetings

Feedback from the carer’s groups was built into each workshop to ensure all participants remained focused on the experience of the current system from the customer point of view.

Several carers provided written personal accounts and commentary of their experience to date as they sought access to support, diagnosis and services. This proved to be a powerful source of data.

Key messages from carers:

- Timescale to seek formal diagnosis ranged between 2-6 years initial visits to GP experiences varied. Carers questioned why are professionals reluctant to diagnose?
- Carers can feel like traitors when they consult with the GP about their partner if the person with Dementia refuses to acknowledge or is unaware of their presenting needs.
- Crisis point is usually a starting point to seek support
- Person with Dementia can be very upset, confused and angry before and after diagnosis
- Continuity of support is vital this is not built into the current system.
- Diagnosis of Dementia can be seen as a stigma
- Carer’s own health likely to deteriorate, the main carer supports the person with Dementia for a long period of time before formally requesting access to services
- Regular carer respite is vital, in particular specialist day care

Examples of letters received from Carers consulted throughout the workshop process:

Husband and full-time carer for wife

I often wonder whether it's lack of knowledge or the advice of the PCT not to refer patients to the Memory clinics for as long as possible. This will only speed up the process, the patient will need a place in a nursing home earlier and cause more distress to the person looking after their needs.

Needs – an early diagnosis could be achieved by being able to contact the memory clinic directly and make an appointment this would be beneficial to all by having the diagnosis earlier and access to medication which cannot be prescribed by the GPs anyway a lot quicker.

Once on medication, they should remain on it, even if the patient fails to answer more than the ten questions on the memory test as it can be very apparent in behaviour if my wife misses a dose either by accident or she refuses to take it. She can present like a zombie which is very distressing for all concerned. If, in my case, my wife's medication was to stop, then permanent care would be the only answer as I know I would be unable to cope.

Day care – Day care plays a major role in the needs of my wife, since my wife started at Curzon House, day care has provided stimulation, challenges and motivation and she asks to attend all the time. In my opinion, all day care centres should be modelled on Curzon House. The day service officer and her team's knowledge of Dementia and how to meet the needs of sufferers with all the different types of Dementia is clearly evident and essential.

Finance should be given to support these essential services, my home looks like the local art gallery with a very proud wife who takes pride in displaying the work she has created.

Carer needs – To make sure that we are supplied with the most essential safety equipment so we can at least ensure the physical safety of the Dementia sufferer. Having access to respite is essential this includes a day care facility and a longer respite stay. There should be at least one week in every five.

Access to services and all information is key and workshops should be offered to carers as part of the diagnosis process because, at times, we act as qualified staff administering medication in the correct dosage at the approved times, self diagnosing ie. Urine infections, chest infections etc. which could have a massive effect on a person's wellbeing and behaviour.

We also act as psychologists as we have to interpret the everyday changing moods and challenges these bring with no training whatsoever.

Hope this helps.

Wife and full-time carer for husband

Hope my story will be of some interest to you. After a few months of gradual memory loss and several collapses, my husband (aged 88 years) had an MRI scan at the Nuffield. The Neurologist detected signs of Alzheimer's and assured us there was no connection with the collapses.

The doctors at Upton Lea Old people's hospital have seen my husband several times and each time say he has not got Alzheimer's. No medication was prescribed, there are no further appointments and the psychiatric nurse has ceased to visit support and I was very upset.

The doctor has tried to diagnose the cause of my husband's frequent collapses (39 in 18 months). Another doctor is also involved and, despite ECGs, Tip tilt table, MRI and ten days in hospital, the collapsing goes on.

We go to the Countess of Chester hospital tomorrow to have a cardiac event recorder fitted.

Looking back, I realise no-one told me of any allowance to which we were entitled. It was quite by chance that a friend mentioned the Attendance Allowance, some months later I learned about the reduction in the Council Tax (both were back-dated).

The Alzheimer's Society (outreacher) has been a wonderful support. I meet other carers at the month 'drop-in' coffee morning and I now have a befriender who visits me at home. She cared for her late mother, I do appreciate her friendship.

The Community Matron, has been a great help this last 12 months and has assisted me when I had trouble with the gas board etc. I am always delighted when she comes.

Curzon House, with Day Service officer and her team have been invaluable help and I am very grateful.

We have a lovely family, unfortunately somewhat scattered, my neighbours are very caring (I even have regular dog walkers!) Fortunately my husband is never frustrated, always content and happy in the present. If we manage to sort out the reasons for his collapses I can cope with the memory loss.

Thank you for your interest.

Wife and full-time carer for husband

I first noticed that my husband was losing concentration when driving. He had always been a careful driver but suddenly would turn off the motorway and we would finish miles away from our destination.

He then began to become vague about dates and times of appointments he had to attend.

I encouraged my husband to see his GP, which he did. The GP told him there was nothing wrong with him and advised him to take up a hobby or a part-time job. This was in September 2005.

A month later, we returned to the same GP and I asked if we could see a specialist.

The GP wrote to Upton Lea Clinic and the appointment came for March 2006 when he was diagnosed with Alzheimer's. My husband is now in hospital as he has deteriorated very quickly. I just hope that other patients can be treated more promptly.

We have had excellent service from the Community Psychiatric Nurse, nurses, social workers and carers

4.4 Mental Health Local Enhanced Service network

Throughout the consultation process the Head of Mental Health from the Integrated Strategic Commissioning Team, regularly engaged with the lead GPs to inform the strategy. This included a presentation from a number of carers who shared personal accounts of their experiences which were both positive and negative around access to support, diagnosis and services.

5 Financial overview

As mentioned in section 3 it has not been possible to extrapolate accurate costs for the current spend on Dementia however there are two main sources of information, firstly the Intervention Type within Social Care based on analysis of assessment records from the Client Record and Information Services System 08/09.

<u>Key findings</u>

Highest levels of intervention were:

18%	Day Care Adult
18%	Nursing
17%	Residential
14%	Home Care
8%	Home Care block contract

Lower levels of intervention were recorded for:

3%	Family Based Care
3%	Residential Respite
3%	Adaptations and equipment
2%	Direct Payments
1%	Intermediate Care (see Appendix 9)

The second source of financial information was collated via an interrogation of the Adult Social Care and Health, Primary Care Trust systems and the Alzheimer's Society Baseline assessment report. Where Dementia costs could not be directly attributed a figure of 55% of total spend was used. Guidance from the University of Kent Personal Social Services Research Unit study has also been applied where applicable at 7.9**%** (see Appendix 10)

From the information received it is clear that currently, the vast majority of spend is on residential and nursing care both via Social Care (£9.7m) and via the Primary Care Trust (£2.5m on Continuing Health Care). Spend on preventive services is at a much lower level, for example, Local Authority support to the third sector (£74k) and Primary Care Trust (£15K).

Other identified spend relates to services which help support people with Dementia to remain in the community, for example:

- Total domiciliary spend is £1m
- Assessment and care management is £300,00 (pro rata figures)
- Older People's Mental Health Services, £1.62m
- Extra Care Housing, £41,548
- Direct Payments £165,133
- In-house day service provision – older people, £44,981 (assumed at 55%)
- Intensive Home Treatment £100,000
- Respite £640,000
- Specialist Dementia Day Care £165,163
- Prescriptions via the Primary Care Trust is £50,000.

The above is not an exhaustive list and further work is required.

6 Strengths and weaknesses of the ‘As Is’

Workshop two of the Care Services Efficiency Delivery methodology invited the participants to identify the range of existing local services, the needs they support and their strengths and weaknesses. The participants were divided into four groups for this task. See Appendix 10

6.1 Gap analysis

Each of the four groups was asked to rate the existing services using the following criteria:

Full gap: where a care or support need is not met at all by any services
Partial gap: where a need is met in part only e.g. a 9am-5pm service may exist to meet a need that is triggered 24/7
Inadequate: where a service does exist to meet the need identified but where the quality of support or service is rated as weak.
Inefficient: where needs are met but the cost of meeting them is high.

Analysis of reasons

The findings showed full gaps for:

- Out of hours support
- Specialist Dementia homecare
- Residential care for younger people
- People over 65 years of age not eligible for Carer’s Allowance
- Primary prevention information – information required about healthy ageing
- Specialist primary support for Dementia
- Legal and financial planning support
- Lack of understanding by professionals of the Dementia pathway
- Knowledge of how to maintain skills for people with Dementia
- Better partnership working with local authority leisure services
- No early onset specialist Dementia service for diagnosis and assessment
- Specific service for diagnosis of Dementia – one stop Dementia shop, ability to self refer rather than access to system via GP

Partial gaps included:

- Carer’s support, especially 24/7
- Consistent response from GPs – training needed
- Courses for people with Dementia and their carers to share good practice
- Enhanced provision for early stages of Dementia for adults, regardless of age, based on ‘Chester Locks’
- Enhanced specialist Dementia day care – patchy and not available at the weekend. Needs to be person centred.
- Good quality care in the acute hospital setting including awareness, education and the environment
- Lack of capacity to offer specialist Dementia domiciliary care

- Access to palliative care for people with Dementia – not equitable provision, depends on who refers. No commissioned pathway.
- End of life care on general wards.
- Lack of choice of nursing and residential care homes. Lack of capacity in some areas. Costs prohibitive.
- Continuity of care from beginning to end. Current pathway encourages the person with Dementia to move as the illness progresses.
- Service for younger people with Dementia.
- People with mild learning disabilities who develop Dementia and are not eligible for support from the specialist team.
- Lack of intermediate care for people with mental health and Dementia
- Good quality prevention information.
- People who self fund including people with Continuing Health Care needs are aware of their right to reassessment as needs change.
- No clear pathway for assessment and diagnosis for early stage. Pockets of good practice and some duplication. Clear signposting is required.
- Occupational therapy – good services but long waiting times. Provision in need of redesign to ensure clear pathway.
- Insufficient capacity in clinical psychology – 2 people for Cheshire West and Chester.
- Counselling capacity.
- Community Mental Health Team – no weekend provision. Needs to be more integrated. No referral back to GP if Dementia progresses.
- Continence service – orders placed every 3 months but needs of the individual can change within that period.

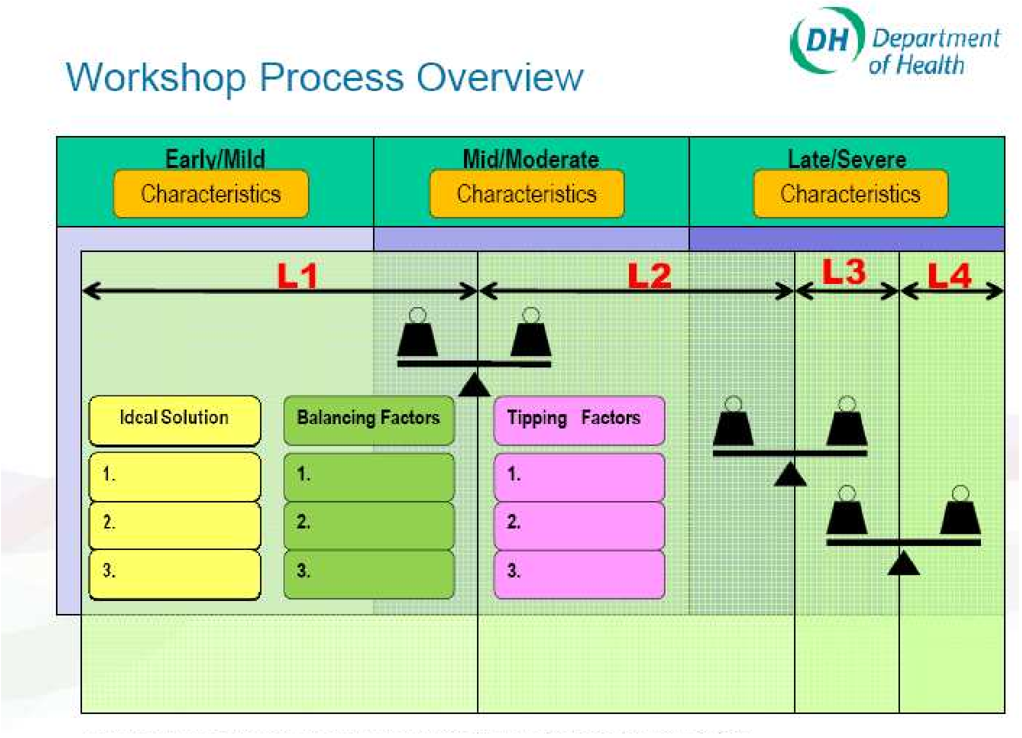
Inadequate comments included;

- Respite care needs to meet individual needs and be more flexible
- GP availability good but the service does not fully meet needs due to lack of knowledge, training and awareness and lack of standardisation in approach, including Out of Hours.
- Complex needs people with severe needs may be living in inappropriate places
- Joined up approach to Dementia Awareness Week

Inefficient comments included:

- Better first point of contact response – need more at times than just signposting people – may need help.
- Where do carers go for help? Emergency services used inappropriately

7 Tipping and balancing factors

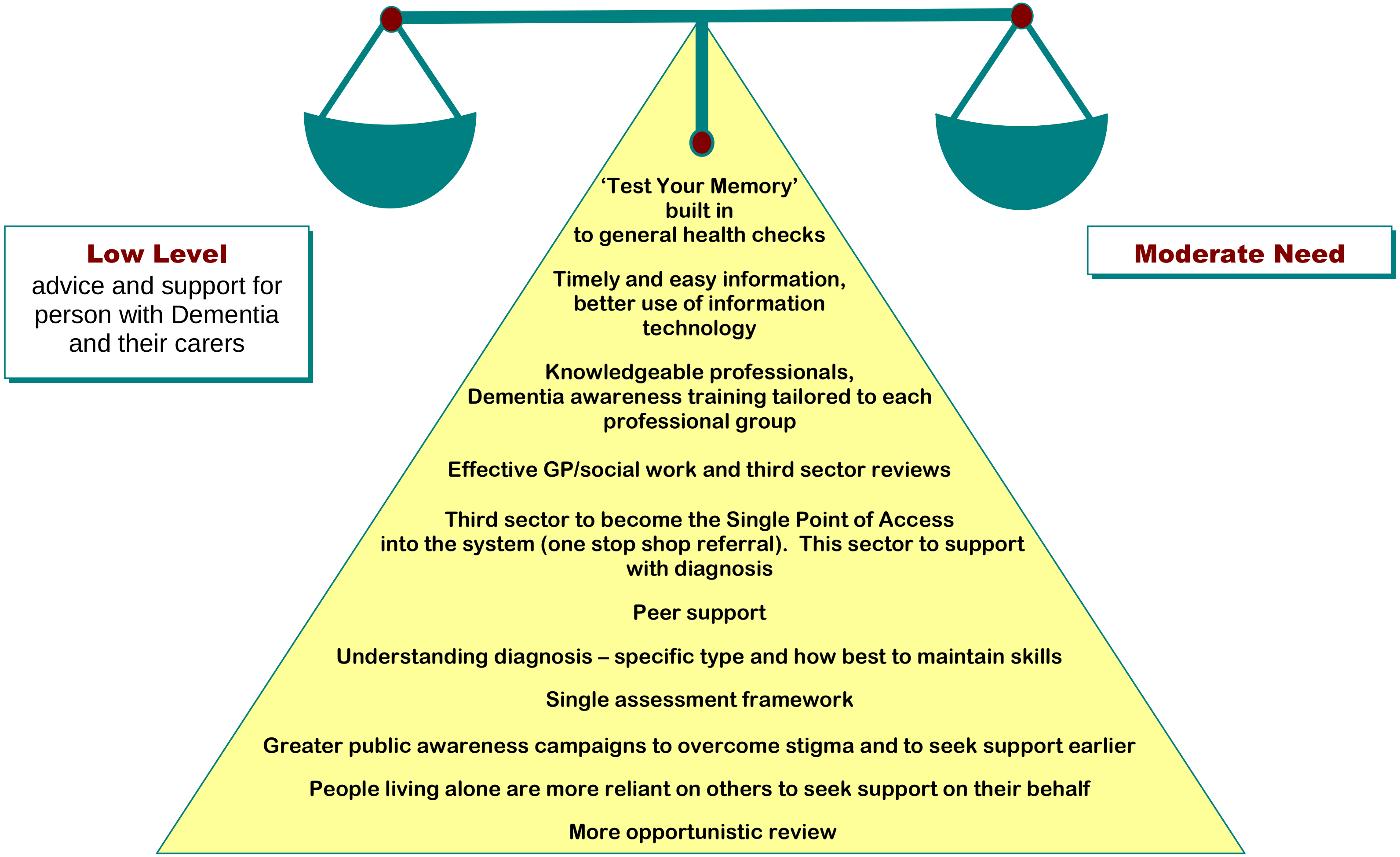


The diagram groups people with Dementia into four levels according to how developed their Dementia is:

- Level 1 – mild
- Level 2 – moderate
- Level 3 – late stages of living at home
- Level 4 severe and complex needs managed in an alternative setting such as residential, nursing or hospice.

Workshop participants were asked to identify Tipping factors (risks that speed up the progression from one level of need to another), in the pathway and how each one could be counter ‘balanced’ to avoid either the support needs escalating or so that any escalation in support needs is only temporary. The assumption was that certain risks ‘tipped’ people from one level to the next and that normally the level and cost of support increased. The aim therefore was to enable people to stay at lower levels for longer.

The diagram below identifies the balancing factors to counter the tipping effect of people moving from Level 1 to Level 2



Low Level
advice and support for person with Dementia and their carers

Moderate Need

'Test Your Memory' built in to general health checks

Timely and easy information, better use of information technology

Knowledgeable professionals, Dementia awareness training tailored to each professional group

Effective GP/social work and third sector reviews

Third sector to become the Single Point of Access into the system (one stop shop referral). This sector to support with diagnosis

Peer support

Understanding diagnosis – specific type and how best to maintain skills

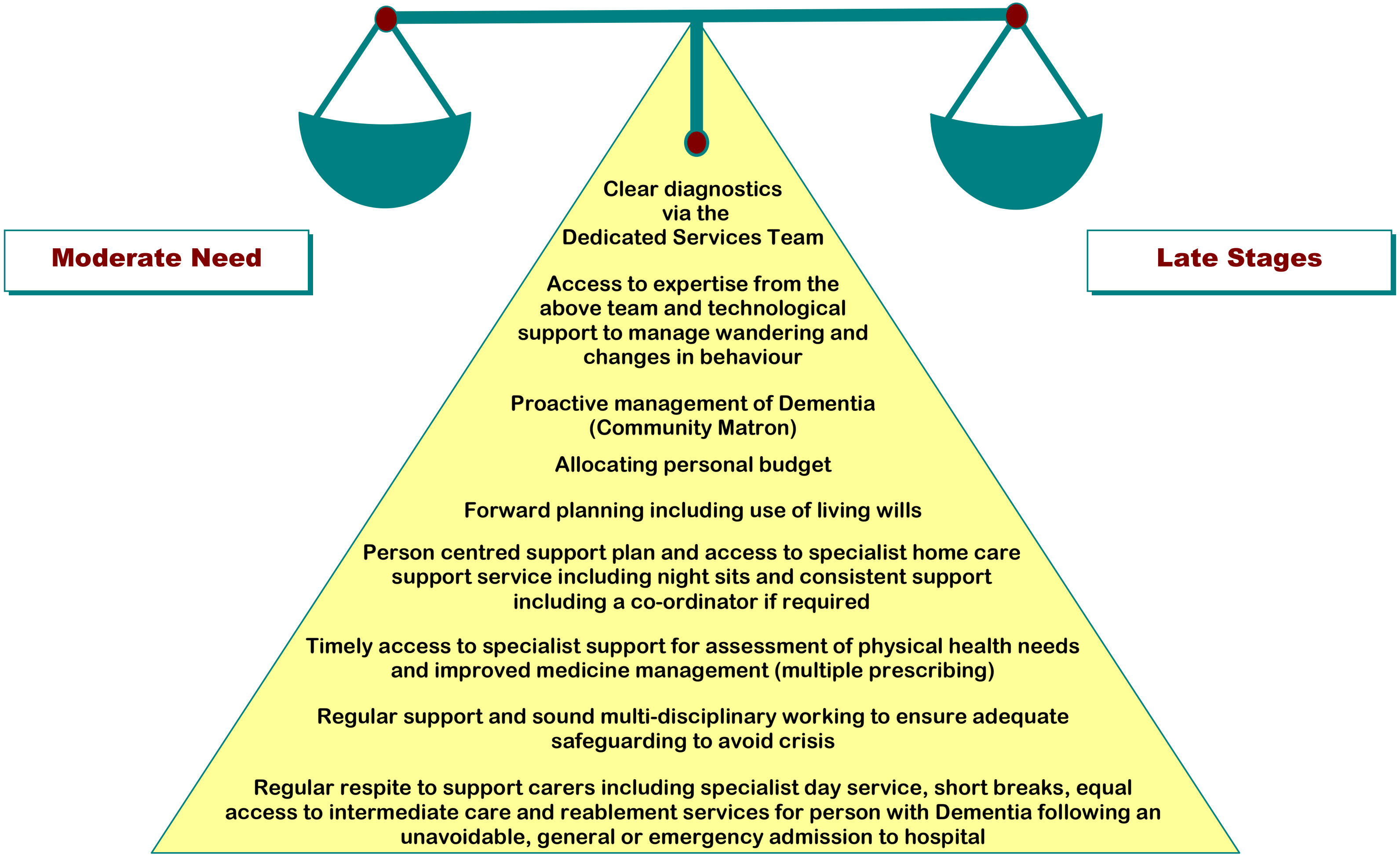
Single assessment framework

Greater public awareness campaigns to overcome stigma and to seek support earlier

People living alone are more reliant on others to seek support on their behalf

More opportunistic review

The diagram below identifies the balancing factors to counter the tipping effect of people moving from Level 2 to Level 3.



Moderate Need

Late Stages

Clear diagnostics via the Dedicated Services Team

Access to expertise from the above team and technological support to manage wandering and changes in behaviour

Proactive management of Dementia (Community Matron)

Allocating personal budget

Forward planning including use of living wills

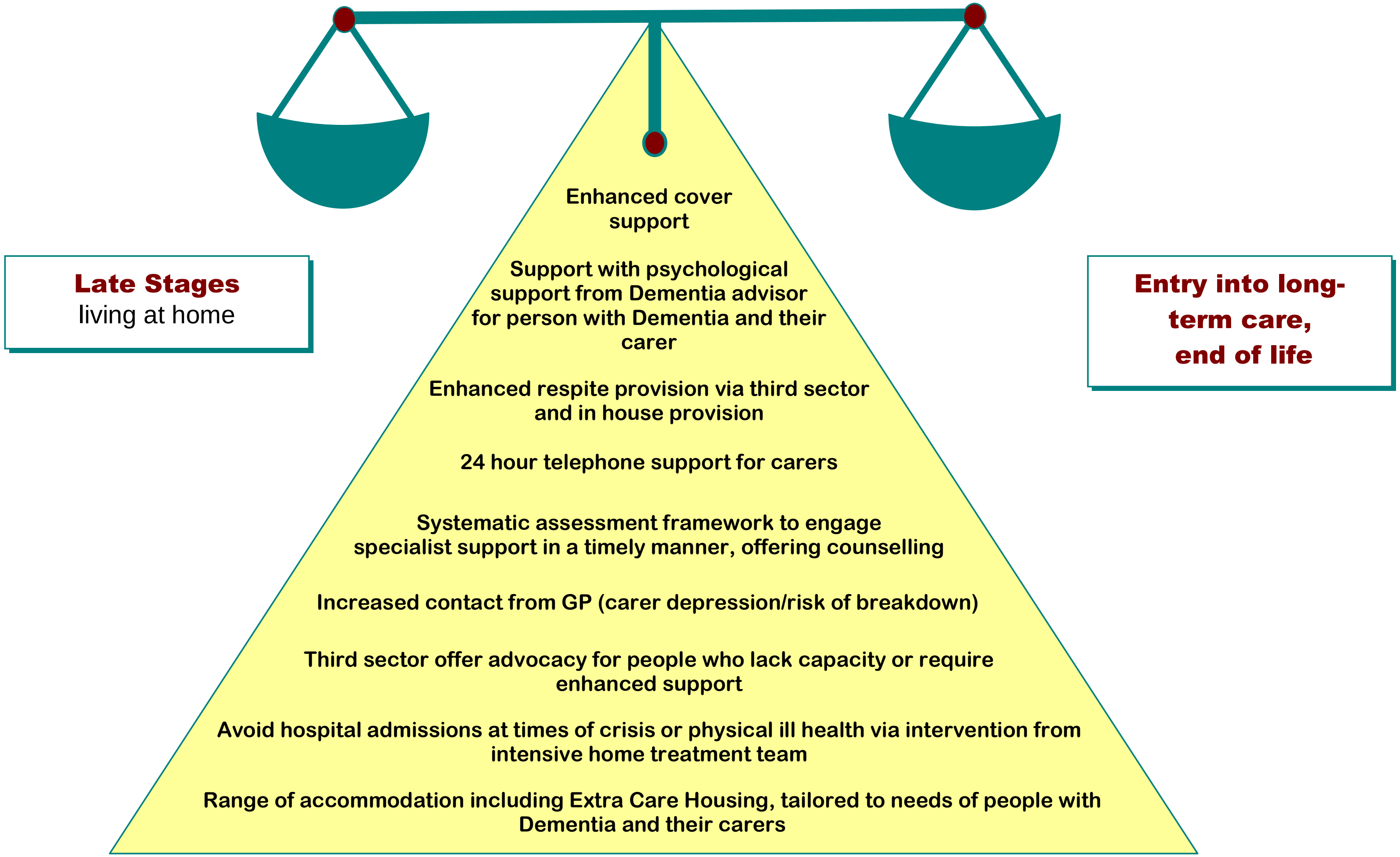
Person centred support plan and access to specialist home care support service including night sits and consistent support including a co-ordinator if required

Timely access to specialist support for assessment of physical health needs and improved medicine management (multiple prescribing)

Regular support and sound multi-disciplinary working to ensure adequate safeguarding to avoid crisis

Regular respite to support carers including specialist day service, short breaks, equal access to intermediate care and reablement services for person with Dementia following an unavoidable, general or emergency admission to hospital

The diagram below identifies the balancing factors to counter the tipping effect of people moving from Level 3 to Level 4.



Late Stages
living at home

Enhanced cover support

Support with psychological support from Dementia advisor for person with Dementia and their carer

Enhanced respite provision via third sector and in house provision

24 hour telephone support for carers

Systematic assessment framework to engage specialist support in a timely manner, offering counselling

Increased contact from GP (carer depression/risk of breakdown)

Third sector offer advocacy for people who lack capacity or require enhanced support

Avoid hospital admissions at times of crisis or physical ill health via intervention from intensive home treatment team

Range of accommodation including Extra Care Housing, tailored to needs of people with Dementia and their carers

Entry into long-term care, end of life

8 Priorities for change

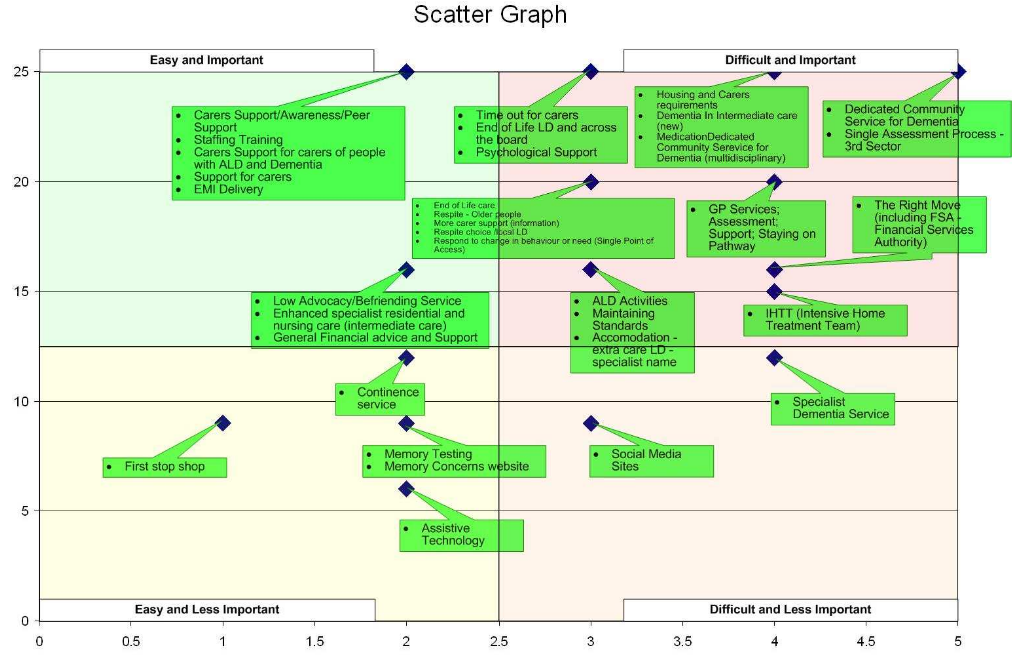
Workshop four of Care Services Efficiency Delivery focused on refining the 'to be' model and vision for the future. This included production of numerous new or revised Service Specifications which are summarised in Appendix eleven. All participants were asked to review the commissioning choices and rationalise the recommendations based on four criteria:

- Desirable - are customer focused and will improve the pathways' effectiveness and efficiency
- Feasible – can be implemented
- Are they all needed – any duplications
- Acceptable – to stakeholders and decision makers

Participants ranked the recommendations for service specifications using a risk benefit analysis:

This included rating the importance of each recommendation in the eyes of people with Dementia or their carers, considering the likely impact of the recommendation and how difficult each would be to implement.

The output from this exercise was the production of a Scatter graph as shown below.



The Scatter graph classifies the Service Specifications into one of four groups:

- easy and important
- difficult and important
- easy and less important
- difficult and less important

Easy and important
Highest scoring specifications in the easy and important category were:

- carer support/awareness/peer support
- staffing/training
- carers- support for carers of people with learning disabilities and Dementia
- support for carers
- EMI delivery.

Specifications for:

- low level advocacy /befriending service
- enhanced specialist residential and nursing care (Intermediate Care)
- general financial advice and support

Were also rated in the mid level of this category

Difficult and important
Highest scoring specifications in difficult and important category in order of priority included:

- dedicated community service for Dementia
- single assessment process to include the third sector
- housing and carer's requirements
- Dementia in intermediate care new service
- medication dedicated community service for Dementia (multidisciplinary)
- time out for carers
- End of life learning disabilities across the board
- psychological support
- mid scoring specifications in difficult and important category included
- The Right Move (includes Financial Services Authority)
- GP services: assessment and support (staying on pathway)
- end of life care
- respite for older people
- more carer support (information)
- respond in change in behaviour or need (single point of access)
- choice of local respite for people with learning difficulties

Lower scoring specifications in this category included –

- Intensive Home Treatment Team
- maintaining standards
- ALD activities
- accommodation/ extra care housing for people with learning disabilities

Easy and less important
Specifications in this category included:

- Continence service
- memory testing
- ‘Memory Concerns’ website
- First Stop Shop
- assistive technology

Difficult and less important
The two specifications in this category were:

- Specialist Dementia service
- social media sites

9 Links to other strategies

The vision set out in the Department of Health publications, ‘*Our health, our care our say’* and ‘*Putting people first: a shared vision and commitment to the transformation of adult social care’* and the new ‘*Equity and excellence: Liberating the NHS’*, seeks to move to a developed system of prevention and community based care where people are in control of their health and care. In order for this vision to succeed, the challenge of Dementia both now and in the future needs to be addressed. The Care Services Efficiency Delivery methodology interfaces with ‘*Equity and excellence: Liberating the NHS’*. The vision for ‘*Equity and excellence: Liberating the NHS’* places a clear emphasis on commissioning for improvement in health outcomes. By focusing on people with Dementia’s health and wellbeing outcomes, partners in Dementia care can contribute to improved outcomes for the whole population for the future.

The process was led by the Health and Social Care Integrated Commissioning Team and included engagement of all key stakeholders, notably community partners, clinicians and professionals (including the Mental Health Local Enhanced Service network) and representation from service users and carers. The methodology systematically ensured an assessment of local needs and services and offered a framework to prioritise investment.

The engagement of key stakeholders laid the foundations to stimulate the market and to promote the need for whole system redesign to champion a shared vision and inform the strategy for the current and future pattern of services and experiences for people with Dementia and their families to achieve improvement and innovation. The identification of service specifications supports the procurement process and assists in making sound financial investments. (Appendix 11).

At the time of writing the local Dementia Strategy, the National Institute for Health and Clinical Excellence has consulted on 18 draft quality statements, each with associated quality measures. These standards will cover care provided by health and social care staff who have direct contact with people with Dementia in hospital, community, home-based, group care, residential or specialist care settings. Once these have been fully launched we would need to ensure these are embedded in the Implementation Plan.

NHS North West has issued guidance for the Operating Framework for 2010/11. The production of this strategy is our local response to the National Dementia Strategy and as discussed earlier, the Care Services Efficiency Delivery methodology has ensured that negotiations with partner agencies have been at the heart of the process.

At a local level, Cheshire West and Chester Council and NHS Western Cheshire have established an Integrated Strategic Commissioning Team. This infrastructure will ensure that connections with all other local strategies are identified and joint action plans approved. As stated in the introduction, the key links will be Review of the Third Sector and emerging Third Sector Strategy. The key priorities are the creation of an Information and Advice Consortium to provide a comprehensive information and advice service, reliable and accessible respite and, where appropriate, support main carers to remain in or return to employment. The introduction of personalised and tailored support plans commission the Third Sector to continue to provide a robust brokerage support service. In line with statutory responsibilities, develop robust safeguarding to include protection of vulnerable adults which will include appropriate informal and formal advocacy as necessary.

Cheshire West and Chester Council is currently developing an Ageing Strategy which highlights the need for early intervention and prevention services, promotes health and wellbeing and Active Ageing, this is being developed in partnership with the Third Sector and user led groups. The aim is to maximise independence, ensure people remain fit, well, and stimulated, to sustain them in the community for as long as possible to avoid an individual’s needs escalating prematurely into higher cost provision.
The creation of extra care housing developments is part of the local Housing Strategy which includes promotion of Assistive Technology. This should help to meet the future housing needs of people with Dementia and their main carers (see specification). Negotiations have commenced with the housing provider to develop a Dementia café and an alternative base for the Dementia clinic.

Work has already commenced to stimulate the market to ensure in house providers specialise in the delivery of a domiciliary and short break re-ablement service as part of the intermediate tier. In addition to the above a specialist respite provision for people with dementia will form part of the Community Support Centre Strategy and opportunities for an integrated workforce will be fully explored.

Personalisation forms a crucial element of the Contract reviews of Independent providers of domiciliary, residential and nursing homes they will need to ensure the workforce is skilled in the care and support of people with dementia.

Transforming Communities focuses on the redesign of services to avoid hospital admission and support timely discharge from hospital. This will involve the creation of an integrated provider service. Intermediate care for people with Dementia requires more dialogue and innovation as once someone with Dementia enters the acute setting this can have a negative effect on their wellbeing and their longer term ability to remain in the community. The above strategy also includes end of life and mental health which have clear links to the Dementia Strategy.

An integrated workforce strategy will help to address the needs of all tiers of staff involved in the delivery of a comprehensive Dementia pathway this will include assessment, care management and providers.

This strategy has been developed alongside the local Learning Disability Strategy with the aim of developing a seamless pathway.

Links have also been established with lead officers for rural communities. The Dementia Strategy will need to demonstrate it can support people who are hard to reach via the Dementia Advisor Role and work is already in hand to ensure all Equality Impact Assessments respond to the rural and age proof requirement.

10 Implementation plan/recommendations

A new model has emerged, known as the ‘Windscreen’. For details see Appendix 12.

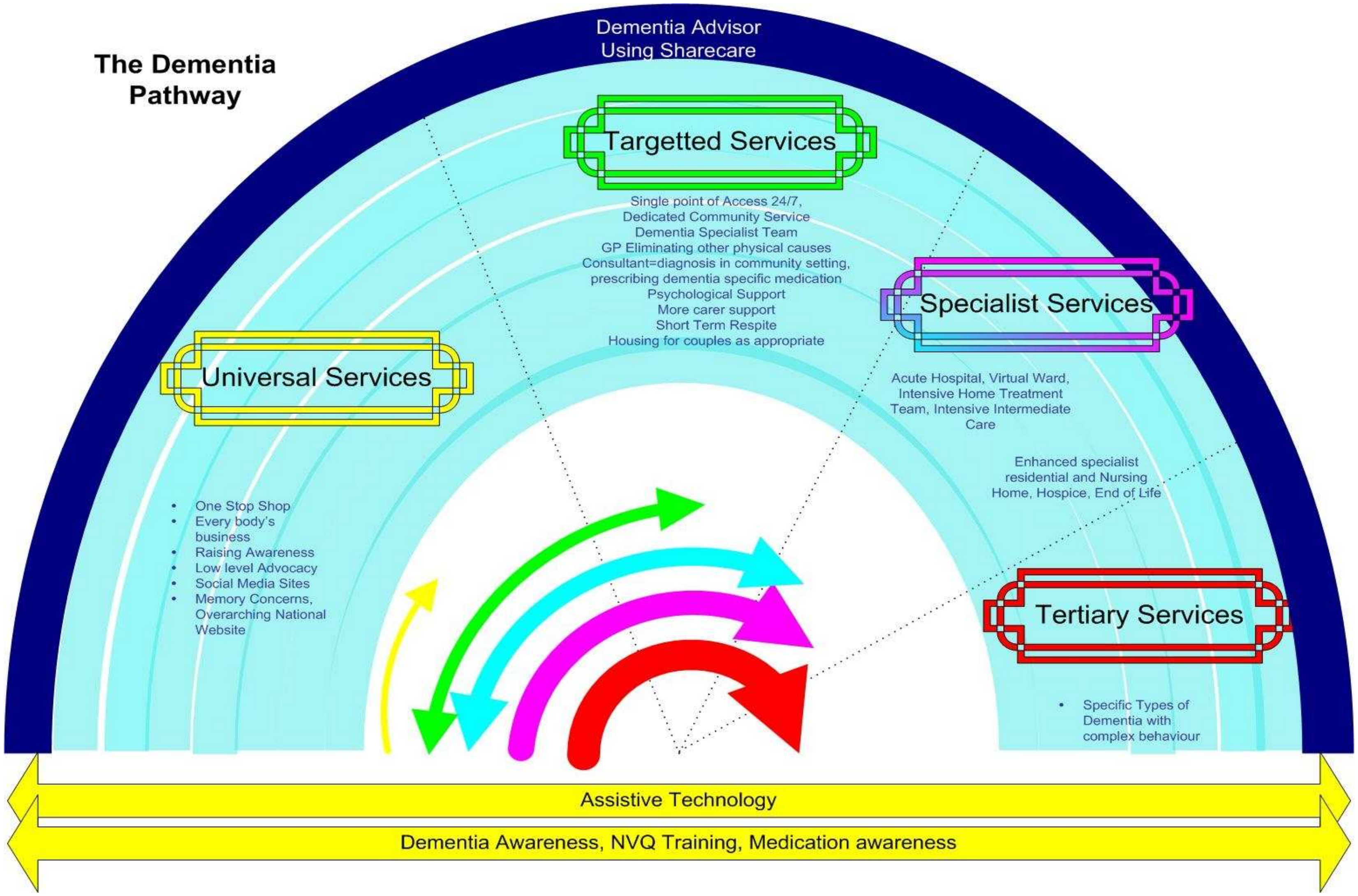
The project team collated the ideas to form the new model and consulted with all key stakeholders. The final workshop prioritised the options applying the Risk Benefit Analysis approach.

The new model has four key components: Universal, Targeted, Specialist and Tertiary Services. It aims to redistribute the current spend with greater investment in the Universal Services which seek to address the prevention and early stages of the illness.

The Dementia Advisor provides overarching support throughout the whole pathway. ShareCare - single assessment tool is applied to all settings to enhance communication and care co-ordination. Assistive technology is accessed as appropriate throughout the pathway and staff in all settings need Dementia awareness and medication awareness training appropriate to their role. A dedicated support team sit within the Targeted Services and service users and carers seek support as and when needed/appropriate. The Specialist Team also provide in-reach support to advise other secondary care providers such as ‘acute’.

The model demonstrates the movement of customers up the pathway as their support needs increase. The emphasis of the model is to use specialist skills to support individuals in their own home with support from universal services for as long as possible only moving individuals along the pathway when their needs can no longer be met in this way.

The Dementia Pathway



Dementia Advisor
Using Sharecare

Universal Services

- One Stop Shop
- Every body's business
- Raising Awareness
- Low level Advocacy
- Social Media Sites
- Memory Concerns, Overarching National Website

Targetted Services

Single point of Access 24/7,
Dedicated Community Service
Dementia Specialist Team
GP Eliminating other physical causes
Consultant=diagnosis in community setting, prescribing dementia specific medication
Psychological Support
More carer support
Short Term Respite
Housing for couples as appropriate

Specialist Services

Acute Hospital, Virtual Ward, Intensive Home Treatment Team, Intensive Intermediate Care

Enhanced specialist residential and Nursing Home, Hospice, End of Life

Tertiary Services

- Specific Types of Dementia with complex behaviour

Assistive Technology

Dementia Awareness, NVQ Training, Medication awareness

This section describes in more detail how a person with Dementia and their carer move through the pathway.

10.1 **Scenario**:

Retired couple living independently in their own home and not known to the system. The wife has her own physical health needs and sees her GP for reviews of her medication for high blood pressure and angina. Her husband is physically well and likes to go to town to socialise. Over a period of time the wife notices that her husband is becoming forgetful, especially when they are out in the car and on occasions he becomes easily distracted from the task in hand.

Universal services

The wife shares her concerns with her friend who suggests she approaches the local Information Point who signpost her to the local Alzheimer's Society One Stop Shop who provide her with advice. They suggest using the memory concern self assessment tool which she can access on-line at home or with support from a Dementia Advisor who is based at the local shop. They also offer some advice around how to maintain skills and stress the importance of stimulation.

The wife, with support from her daughter, completes the self assessment tool on behalf of her husband.

The wife is due to see the GP for a regular check up of her own physical health. She mentions her concerns and refers to the self assessment tool. Her husband is not aware of his forgetfulness. The GP invites them both in to the surgery for a general health check and incorporates a further memory test, which is the agreed tool amongst all GPs in the area. The outcome of the test indicates a need for regular monitoring and tests to eliminate other causes. The GP suggests a referral to the Alzheimer's Dementia Advisor's Service and explains that this organisation have become the main support for people and entry point into the system. The referral is made using Shared Care.
The Advisor arranges a home visit and offers education about how best to meet the needs. She also mentions a social group which is targeted at people in the early stages of Dementia and their carers and offers the Carer's Emergency Card.

Following attendance at the above group the wife is made aware of the peer support system.

Dementia advisor

The Advisor is allocated as individuals enter the pathway. They support and access care to respond to need, as per the national role. Dementia advisors are patch based and have good working relationships with the Social Care individual commissioning teams. They are able to refer into the teams on behalf of people they already support in order to enable the team to determine Fair Access to Care eligibility. The patch team undertakes an assessment of need using Shared Care and offers a carer's assessment.

The outcome of the assessment to meet the eligible needs is a small personal budget and the introduction of assistive technology.

Targeted services

The situation is monitored on a regular basis. The Dementia Advisor receives a call from the wife stating that her husband has had a significant change in behaviour and she is struggling to cope. The Dementia Advisor refers her on to the Dedicated Services Team.

This is a multi-disciplinary team who respond within the day and undertake further assessments in the home setting. The intermediate care team are notified and they agree to offer a stepped up support plan which is free at the point of delivery. The GP arranges further tests which identify a urine infection and medication is prescribed. A referral is also made to the Medication Community Clinic which is based at the Extra Care Housing development.

Medication resolves the infection and intermediate care is withdrawn after 2 weeks and the original support plan continues.

Consultant appointments result in a prescription for Aricept and review appointments are made. The wife feels that the time has come to attend a carers' course which has been organised by the third sector with built in respite for her husband. (carer is now attending the Carers' Group on a regular basis).

The Dedicated Community Team support physical and psychological needs as required. Over a period of time the respite offer is increased to include attendance at specialist day care and regular short breaks are built into the support plan. This enables the wife to spend time pursuing her own interests and supports her health and wellbeing. Over a period of time the Dementia advisor starts to discuss longer term planning including raising awareness of both sound financial planning and housing options.

Specialist services

The wife has a heart attack and is admitted to hospital as an emergency. The husband is supported at home by his daughter and the Intensive Home Treatment Team who provide expertise around management of behaviour and physical care as arranged by the Care Co-ordinator from the Dedicated Community Services Team. Following discharge from hospital, the wife returns home and is eligible for a period of re-ablement from the in-house domiciliary service.

The husband's needs are increasing as his memory deteriorates and he starts wandering. The wife does not feel able to cope. The Dementia Advisor and multi-disciplinary support team re-assess needs and increase the care package whilst a tenancy is sought in the Extra Care Housing development which the couple have become familiar with from their visits to see the consultant. The couple remain in Extra Care Housing for two years with a combination of the above support services.

The husband's health significantly deteriorates and the wife is no longer able to manage as her own health needs increase. A placement is arranged in a specialist nursing home where all staff have been trained in Dementia. The end of life pathway is discussed with the carer as her husband lacks capacity and her wishes are fully documented and acknowledged. Her husband receives high quality nursing care.

10.2 Next Steps - emerging themes/issues to be resolved

The latter will require commitment to significant service redesign to increase efficiencies and achieve a pathway without significant investment over a number of years as acknowledged by the National Dementia Strategy. Approval will be sought from Primary Care Trust Board and Executive Committee. Having engaged carers and service users in the process they are keen to receive feedback following the production of the strategy and have high expectations that the new model will be implemented.

10.3 How will it work? Recommendations for implementation

The following represent the key components that are required to lay the foundations to build a good local Dementia care system.

- Develop a local training programme to raise awareness for the public and professionals
- Introduce web access and digital media for self assessment 'test your memory online' tools and peer support and learning networks
- Ensure that Dementia prevention information is integrated into mainstream public health work and that it is part of an early intervention and prevention strategy.
- Standardise the use of primary care assessment tools, maximising the opportunities for assessment through health checks and other routine appointments
- Invest in the 3rd sector role to provide early advice, ongoing support and advocacy through the introduction of a Dementia Advisor. The Dementia Advisor role would incorporate early intervention and on going care co-ordination as needs increase. The Advisor would support the assessment process, if not already commenced and have a dual role to support carers and recognise their 'role' and rights.
- Develop the care market to be equipped to respond to greater use of personalised budgets and the range of provision available for people with Dementia.
- Drive up the quality of provision via a Community Dedicated Resource Team supporting provider staff and acting as role models.
- Develop a single point of access which is available 24/7 including assessment and coordinating the care for individuals with Dementia across the health and social care system

- Ensure Dementia care is delivered in a person's own home where ever possible, including diagnosis and medication reviews, avoiding hospital attendance and possible admission through good care management and through appropriate stepped up/stepped down physical and mental health support
- Greater use of assistive technology at all stage of the illness
- Assess the requirements for future housing developments and consider the needs of people with Dementia and their carers
- Establish a dedicated Dementia resource through re commissioning older people's mental health services with appropriate roles and skills to support a wider pathway
- Promote good coordination of care that supports the use of advance directives to provide a clear end of life pathway
- Ensure access to financial and life course planning for all in later life or at transition points, including carers and including equity release and housing options advice
- Use recognised good practice guidance to inform local service development
- Introduce local Dementia champions across a wide range of areas e.g. within the departments of the Countess of Chester hospital, GP practices and independent sector providers.

10.4 Implementation

The above recommendations will be developed into 8 business cases and these will be prioritised by Cheshire West and Chester Council and NHS Western Cheshire. Once approved, a small group of stakeholders will be established as a Steering Group. Their role will be to oversee the implementation and monitoring process. Individual Business Case Outlines will be further developed with relevant lead officers and it is envisaged this will include further engagement with relevant stakeholders to ensure the implementation is effective.

It is anticipated that the implementation process will be completed over an 18 month period commencing September 2010 following approval from the PCT Board in September.

At a national level the work will be scrutinised by a network of Dementia Programme leads and completion of tools such as the Dementia Census. At a local level there will be continuous evaluation of any new developments.

11 Equality impact assessment (see Appendix 13)

The template which has been adopted by NHS Western Cheshire has been completed in respect of this strategy.

12 List of appendices

- Appendix 1 - list of Dementia types source Dementia what every commissioner needs to know.
- Appendix 2 - People aged 65 years and over predicted to have Dementia - Joint strategic Needs Assessment (JSNA).
- Appendix 3 - Dementia projections for Cheshire West and Chester 2025- (JSNA)
- Appendix 4 - Dementia Count in Cheshire West and Chester by Town - Quality and outcomes framework – General Practice Registers
- Appendix 5 - Age at intervention – Client Record and Information Services System
- Appendix 6 - Five Workshop Model – Care Services Efficiency Delivery
- Appendix 7 - ‘As is’ – Cheshire West and Chester workshops
- Appendix 8 - Findings from Surveys - Alzheimer’s Society
- Appendix 9 - Care Plan Interventions – Client Record and Information Services System
- Appendix 10 – Strengths and weaknesses
- Appendix 11 –Summary of Service Specifications
- Appendix 12 – Windscreen model including costings
- Appendix 13 - Equality Impact Assessment

Appendix 1

Dementia types

Types of Dementia

There are different types of Dementia caused by different diseases of the brain. Because these diseases affect the brain in different ways, they produce different symptoms. Some of the most common forms of Dementia are listed below.

Alzheimer's disease is the most common type of Dementia. It changes the chemistry and structure of the brain, causing brain cells to die. In the early stages of Alzheimer's, the person's behaviour may change in very small ways. For example, they may start forgetting things or repeating themselves more often than usual. At first, people often attribute these symptoms to factors such as ageing, stress or bereavement.

In the middle stages of Alzheimer's, the person may need reminders to carry out activities of daily living such as eating, dressing or using the toilet. The person's memory will get worse, and they may have difficulty recognising familiar people or places. Over time, the person will become increasingly dependent on others for help. They are likely to experience severe memory loss and become increasingly frail. They may have difficulty with eating, swallowing, continence and experience loss of communication skills such as speech.

Vascular Dementia is caused by strokes or small vessel disease, both of which affect the supply of oxygen to the brain. Vascular Dementia affects people in different ways. It can cause communication problems, stroke-like symptoms and acute confusion. The symptoms that a person experiences as a result of a stroke depend on which part of the brain has been damaged. For example, if the damaged area is responsible for movement of a limb, paralysis may occur. If the part of the brain damaged is responsible for speech, the person may have problems communicating.

When vascular Dementia is caused by as single stroke, it is called single-infarct Dementia. Vascular Dementia is more commonly caused by a series of small strokes. These can be so tiny that the person may not notice any symptoms or the symptoms may be only temporary. This is called multi-infarct Dementia.

Vascular Dementia progresses in a similar way to Alzheimer's disease, but progression is often 'stepped' rather than gradual, declining suddenly as the person has a new stroke. Progression of vascular Dementia may be slowed through the control of underlying risk factors such as blood pressure.

Fronto-temporal Dementia is a rare form of Dementia affecting the front of the brain. It includes Pick's disease and often affects people under 65. In the early stages, the memory may remain intact, while the person's behaviours and personality change.

In the early stages of fronto-temporal Dementia, the person is less likely to become forgetful than in Alzheimer's disease. Instead, their behaviour can change quite dramatically. For example, they may seem more selfish or unfeeling than usual or sexually uninhibited. The later stages are very similar to Alzheimer's disease.

Dementia with Lewy bodies is caused by tiny spherical protein deposits that develop inside nerve cells in the brain. These interrupt the brain's normal functioning, affecting the person's memory, concentration and language skills.

This type of Dementia has symptoms similar to those of Parkinson's disease, such as tremors and slowness of movement. The person may also experience hallucinations. The progression of this condition can be confusing for carers, as the person's abilities may fluctuate.

Source: Dementia: What every commissioner needs to know. Alzheimer's Society 2009.

Appendix 2

People aged 65 years and over predicted to have Dementia - Joint strategic Needs Assessment (JSNA).
Dementia Estimates for Cheshire West and Chester. People aged 65 and over predicted to have Dementia, by age band

National prevalence estimate by age and gender			**Estimated number of people with Dementia in 2007**					
			Cheshire West and Chester	Area Programme Boards				
				Chester	Ellesmere Port	Northwich and Rural North	Rural West	Winsford and Rural East
Men	65-69	**1.5%**	116	25	21	24	26	21
	70-74	**3.1%**	197	44	37	37	45	35
	75-79	**5.1%**	258	62	48	49	56	43
	80-84	**10.2%**	338	87	52	73	73	54
	85 and over	**19.7%**	449	110	67	91	108	72
Women	65-69	**1.0%**	84	19	15	16	19	15
	70-74	**2.4%**	180	43	35	34	38	29
	75-79	**6.5%**	423	109	77	85	85	67
	80-84	**13.3%**	659	171	107	143	136	101
	85 and over	**25.2%**	1,227	310	184	262	270	201
All persons aged 65 and over			3,931	980	642	814	857	637

Note: The prevalence (%) obtained from Dementia UK: the Full Report – a report into the prevalence and cost of Dementia prepared by the London School of Economics and the King's College London for the Alzheimer's Society. Prevalence applied to 2007 Office for National Statistics population estimate

Source: National Statistics website: www.statistics.gov.uk

Appendix 3

Dementia projections for Cheshire West and Chester 2025- (JSNA)

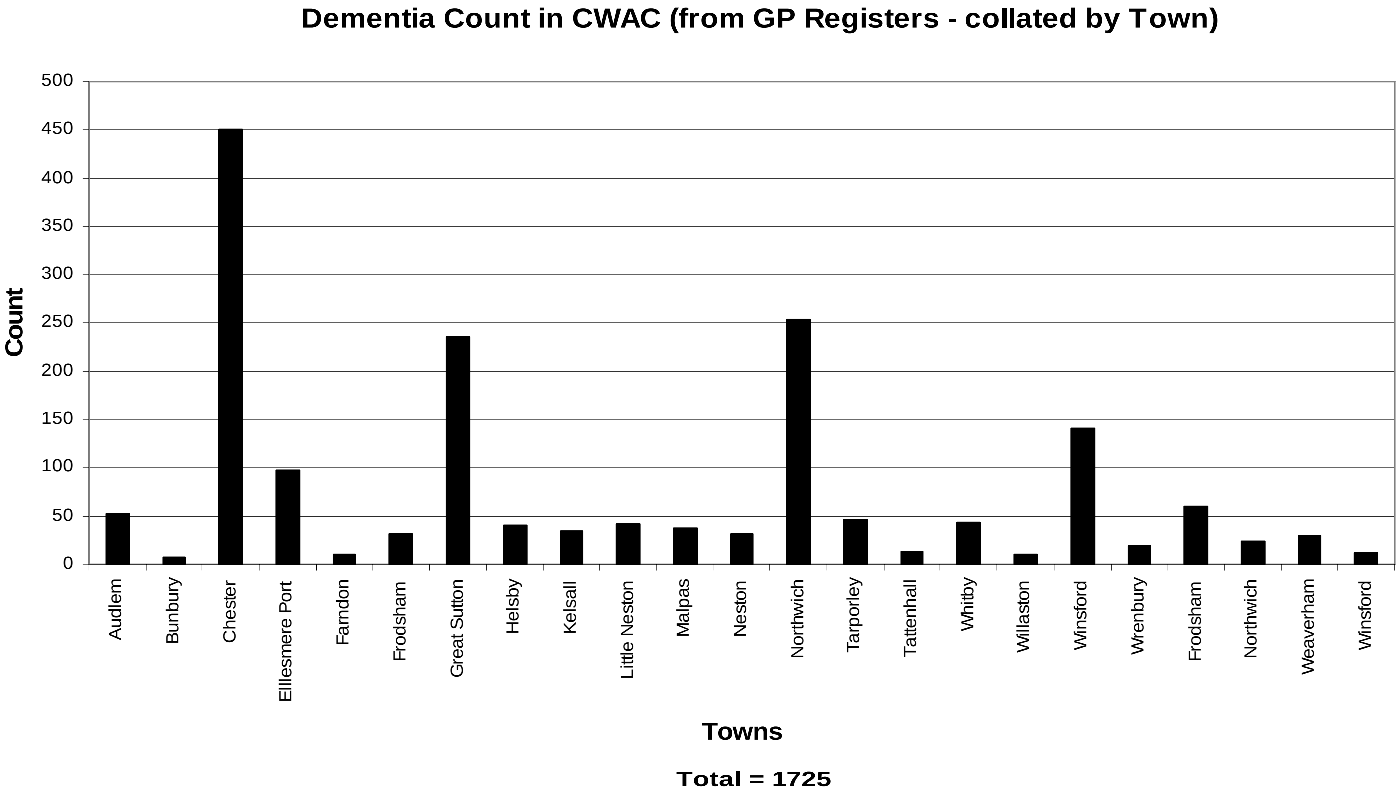
People aged 65 and over predicted to have Dementia, by age band and gender projected to 2025

	2008	2010	2015	2020	2025
Males aged 65-69 predicted to have Dementia	121	130	155	141	149
Males aged 70-74 predicted to have Dementia	204	215	245	294	270
Males aged 75-79 predicted to have Dementia	255	265	306	358	429
Males aged 80-84 predicted to have Dementia	347	368	408	490	582
Males aged 85 and over predicted to have Dementia	492	532	690	887	1142
Total males aged 65 and over predicted to have Dementia	**1,419**	**1,508**	**1,803**	**2,168**	**2,570**
Females aged 65-69 predicted to have Dementia	85	90	110	98	104
Females aged 70-74 predicted to have Dementia	184	190	201	252	223
Females aged 75-79 predicted to have Dementia	424	424	469	508	625
Females aged 80-84 predicted to have Dementia	679	679	731	825	905
Females aged 85 and over predicted to have Dementia	1260	1335	1512	1739	2091
Total females aged 65 and over predicted to have Dementia	**2,631**	**2,717**	**3,023**	**3,420**	**3,947**
Total population aged 65 and over predicted to have Dementia	**4,050**	**4,223**	**4,826**	**5,588**	**6,517**

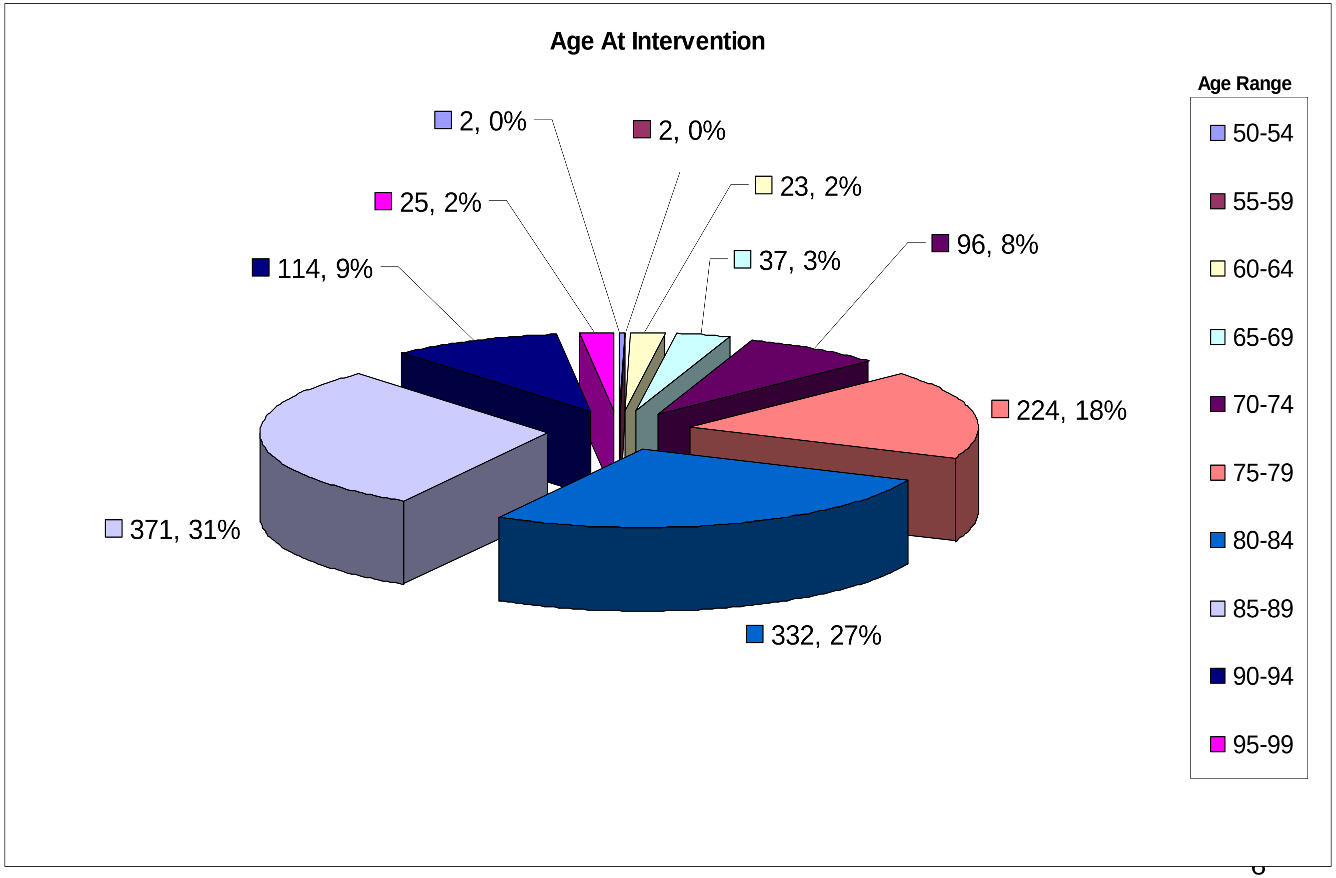
Source: Projecting Older People Population Information System (POPPI): www.poppi.org.uk/

Appendix 4

Dementia count in Cheshire West and Chester by town - Quality and Outcomes Framework – General Practice Registers



Age at intervention – Client Record and Information Services System



Appendix 6

Five Workshop Model – Care Services Efficiency Delivery

“Five Workshop” Model Is Designed To Embrace Integrated Planning/Working

DH Department of Health

W/shop 1 “As is”
Baseline mapping

W/shop 2 “As is”
Validation & analysis

W/shop 3 “To Be”
Gaps & ideal pathway

W/shop 4 “To Be”
Refining the “To Be” pathway.

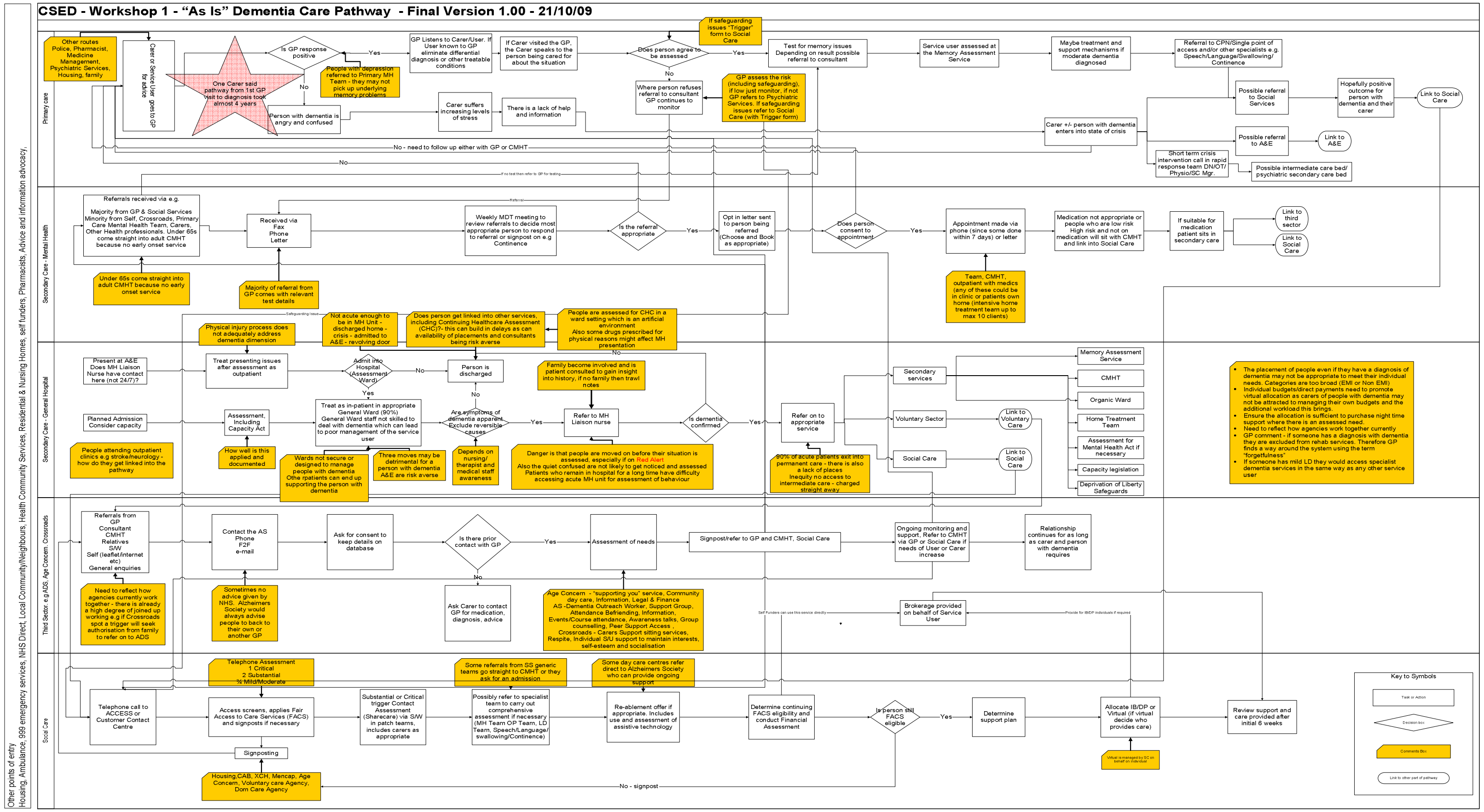
W/shop 5
Prioritisation and action planning

Care Services Efficiency Delivery: supporting sustainable transformation

Appendix 7

‘As is’ – Cheshire West and Chester workshops

Final and Agreed “As Is”



Appendix 8

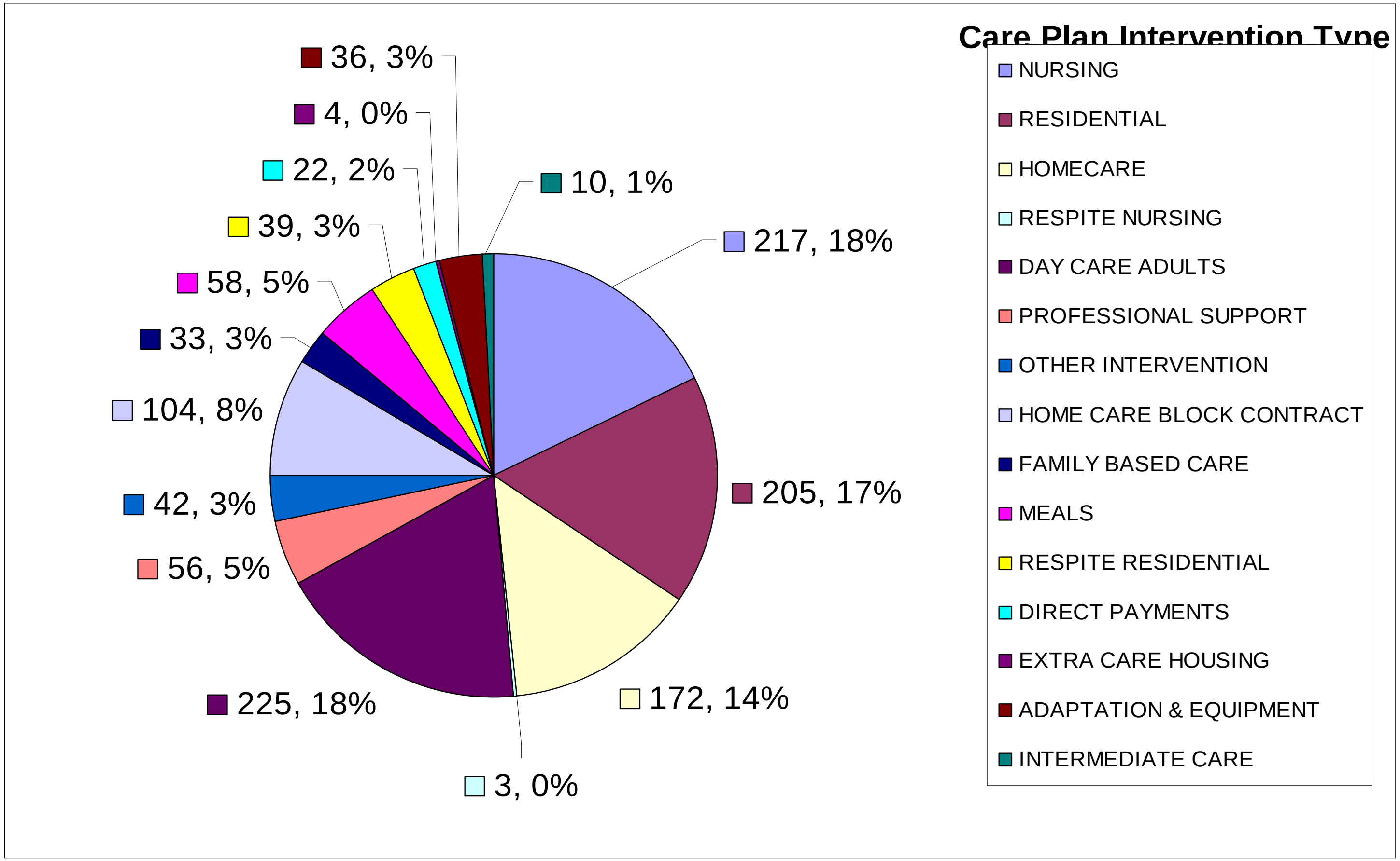
Findings from Surveys - Alzheimer’s Society - Services for people with Dementia

	Type of Activity																	
Provider below	A	B	C	D	E	F	G	H	I	J	K	L	M	Total number supported	People with Dementia	Carers of people with Dementia	Funded by	Area Served
Alzheimer’s East Cheshire			x	x		x	x	x	x			x		436	130	306	various	East Cheshire
Alzheimer’s South Cheshire	x		x				x	x	x					939	257	682	various	South Cheshire
Alzheimer’s Vale Royal	x		x				x		x		x			451	240	211	various	Vale Royal
Alzheimer’s West Cheshire	x		x				x		x					1535	313	1222	various	West and EP&N
Cheshire West and Wirral Crossroads			x									x		132	66	66	WCPCT, CCC, CD/L, SU	West and EP&N,Wirral
Respite breaks for carers, Crossroads East			x											?	?	?	CCC, Other	East Cheshire
Cameo, Crossroads East							x	x						10	10	10	CCC	East Cheshire
Crossroads South (as was) no figures available														?	?	?		
Time Out Groups, Age Concern East			x											80	40	40	CECPCT, SU	East Cheshire
Cheshire Carers Centre - Carers Helpline/Other					x	x	x		x	x				4050	0	350	CECPCT, CCC, Grant BL, CD/L	All Cheshire
Older Peoples Project - Cheshire Carers Centre			x		x	x	x	x	x		x			561	0	400	CCC	East, Central Cheshire
Respite Community Partners			x					x	x					60	60	5	CCC	Vale Royal
St Lukes - FSU Counselling Dept		x												250	0	2	CD/L	Mid and South Cheshire
St Lukes - Time for Me Group			x											30	0	30	Grant BL	Vale Royal, East, South
Family Based Care - Placement Carers Team			x			x	x	x				x		?	?	?		West, EP&N, Vale Royal
Carers Support - Placement Carers Team			x			x	x	x	x			x		200	115	85	CCC	West Cheshire
Macclesfield Live at Home Scheme, Methodist Homes	x							x						100	10	?	CD/L, SU	Macclesfield
Day Care Services, Age Concern Cheshire	x											x		460	60	40	CCC, FR, CD/L, SU	West, South Central
Advocacy, Age Concern													x	200	150	?	CCC	all Cheshire
													Total	**9494**	**1451**	**3449**		

Key to above Types of Activities		**Key to funding sources**
A Befriending	H Outings, day trips and social events	CECPCT Central and Eastern Cheshire PCT
B Counselling	I Support groups	WCPCT Western Cheshire PCT
C Dementia and carer support	J Training for care professionals	CCC Cheshire County Council
D Dementia Cafes	K Training for mixed groups and others	Grant BL Big Lottery Grant
E Telephone help lines	L Day support, home support or purchase of these	CD/L Charitable donations or legacies
F Provision or purchase of breaks, holidays	M Other including Advocacy	SU Services Users are charged for all or part
G Information programmes or information provision		FR Fundraising

Appendix 9

Care Plan Interventions – Client Record and Information Services System



Appendix 10

YELLOW GROUP

Service	Needs supported	Strengths	Weaknesses	Comments
Day care	Social integration	Peer support mechanism for carers	Not suitable for unsociable people	We need to see day care in a broader sense both for PWD and carer
	counteract anxiety	Education for PWD	One size fits all	Need different model for different needs
	Support	Provider structure	Huge variations in quality of care	
	Provider support	Extra benefit when PWD and carer attend together	Accessibility and distance and cost	
	Reduces build-up of stress	Maintaining skills	Lack of privacy	
			Mixes people at different stages	
			Not always well know that is available	
Respite care	Relief for carers	Allows carers space.		Not well structured for PWD
		Some stimulation for PWD	Can exacerbate anxiety	Can be detrimental to them
			Limited choice and flexibility	Needs to be restructured
			Tends to institutionalise	
			De-skills individuals	
			Variable quality	
			Disorientation	
			Cost to patient (£)	
OT	Helps people continue living at home	Maintain skills	support is reducing	

Appendix 10

YELLOW GROUP

Service	Needs supported	Strengths	Weaknesses	Comments
			People have to pay for themselves	
			Tribal approach - some teams not "relevant" to some conditions, leads to variations of care	
			Takes a long time to respond - up to 12 weeks	
Clinical psychology	Diagnosis	Kinder to the PWD than traipsing over to Walton	Good but not enough of it	Referred through Primary Care Mental Health team
	Retaining skills	Breaking bad news		Need to look at how it works alongside memory clinics - each doing what they're good at
	Cognitive rehab to build or compensate for skills	No waiting list - quick response		
	Challenging behaviour	Helps carers cope with challenging behaviour		
Counselling	Denial, coping with the diagnosis	Lets people offload things they would not say to their families	Poor availability of skilled counselling relevant to Dementia	Need to mobilise additional counselling skills from other sources
	Grief and bereavement	Relieves stress	Doesn't appeal to a lot of men. Do they need alternative approaches (the pub?)	Needs to be more frequent courses
	Counselling before death	Sometimes provided informally by practitioners		

Appendix 10

YELLOW GROUP

Service	Needs supported	Strengths	Weaknesses	Comments
Community Mental Health Team	Diagnosis and assessments	Assessment and selection of appropriate referral	Role is confused with EMHT and others	Need a combined CMHT/EMHT
	Support clients with complex needs	Able to co-ordinate care packages	Can't go back to them without going back through the GP	
	Virtual memory clinic	Accessible	Poorly co-ordinated care because of people falling between teams	
Continence Service	Dignity	Relieves stress for PWD and carer	Unresponsive - stress	
	Continue life at home		Not well enough known	
A S	Social content	Understands the needs of PWD and carer, able to gear service to those	Not sufficiently appreciated by other professions (credible life awareness)	Scope and value of AS work needs to be better understood and signposted by other professionals
	Peer support		Coverage is a post code lottery	
	Information and education signposting			
Pharmacist	Ensure medication (all conditions)	Expert on drug interactions	Unable to monitor effectively	
			Dementia drugs come from secondary care so not in packs with all their others	
GP	Exclude generic course	Help relieve stress	Increases stress if not responsive	GP needs to give people choices and then co-ordinate support to meet it

Appendix 10

YELLOW GROUP

Service	Needs supported	Strengths	Weaknesses	Comments
	Co-ordinate medical interventions and other health needs.	Generalists	Often reluctant to refer (think the support and help is of little value)	They need training to deal with psychological /psychiatric issues
	Signposting	Very good at managing medical interventions	Can try to manage it all themselves and not involve other specialists	
	Initial assessment	Interventions	Not always properly aware of Dementia	

BLUE GROUP

Service	Needs supported	Strengths	Weaknesses	Comments
Voluntary sector	Symptom control	Accessibility and response times	Reliance by statutory sector on voluntary sector	Committed and passionate staff
	Advocacy	Time	Capacity	Seen as impartial
	Liaison to statutory services	Holistic	Funding	
	Social support	Specialist level of knowledge		
	Signposting specialist advice, emotional support, practical support	Free – don't turn people away		
		Picks up areas not covered by statutory sector. Navigate the system		

Appendix 10

BLUE GROUP

Service	**Needs supported**	**Strengths**	**Weaknesses**	**Comments**
Nursing homes	24-hour needs	Supports carers	Lack or placement	How to choose
	Physical and nursing care	Continuity of own GP	Poor integration	Rates between private funding and social services
		Support end of life care	Funding	
		Stimulation and structure	Continuity	
			Training	
			Wide variation in quality	
			Speed or placement	
			Private sector	
Social care	Managing isolation	Excellent quality of day care and respite	Limited access	No specialist Dementia home care
	Support for carers	Facilities	Means tested/eligibility criteria	
	Continence	Support at home	Speed of response	
	Eating and drinking		Wide variation in staff – not always reliable response	
	End of life crisis intervention			
	Stimulation – person centred			
Acute care	Managing medical needs	Save lives	Used as respite	Training and numbers of staff

Appendix 10

BLUE GROUP

Service	Needs supported	Strengths	Weaknesses	Comments
	Assessment and referral i.e. Placement of person	Treat acute physical needs	Not specialist in Dementia	Right people who care
		Highly skilled and motivated staff	Designed to meet physical health needs but not mental health needs.	Within acute care there needs to be a procedure unit with appropriate staff
			May not get treated for procedure needs due to Dementia	
			Not good at treating the whole person – could make worse	
			Not secure unit. Bed pressure	
Mental health services	Assessment	Positive support	Declined medical procedure etc.	Don't provide care throughout care pathway
	Risk management	Easy access to specialist help	Security misuse	
	Access to severe clients	Administration staff very helpful – reassuring	Limited resources	
		Specialist access of care and support	Number of people	
			Referral to end of life care	
			Prescribing at secondary care – it should be primary care	
			Delay referring from GP to mental health services	

Appendix 10

BLUE GROUP

Service	Needs supported	Strengths	Weaknesses	Comments
Continuing health care				
Community health services				
Community support services				
Financial and legal services				
Primary care mental health services	Assessment of mental health needs	Carer support	Slow triage process	Problems especially with patients who are terminally ill
		Good ongoing support		
	Single point of access for mental health	A lot of new investment		

Appendix 10

RED GROUP

Service	Needs supported	Strengths	Weaknesses	Comments
Primary care (GP)	Diagnosis	Everyone has a GP	Inconsistent response	When GP contact works well it's very good but the opposite can happen routinely
	Reviews	No stigma visiting a GP	Lack of training/knowledge/ experience	Special interest GP in each practice
	Medication	Not means tested	Conflicting pressures	Dementia register
	Information	Lynch pin referral to secondary care or other services	Resources	
Social services	Multi-disciplinary assessment	Legal accountability to assess for community care	Stigma in approaching department	Change to personalisation
	Provision of service	Experience of providing services	Service led not means led	Agenda is, at present, an unknown
	Home care	Overview of support available	Means tested	Training for social work staff on the range of Dementia support and services
	Short stays		Eligibility criteria	
	Individual budgets		Focus on care management and not social work	
	Carer's assessments		Demand exceeds resources	
	Carer's support/groups/ courses		LGR - locally pressure on staff time	
	Funding to third sector organisations			
	Crisis support			

Appendix 10

RED GROUP

Service	Needs supported	Strengths	Weaknesses	Comments
Third sector	focus on the person, whether it's the person Dementia or the carer	Not seen as the statutory sector	Capacity	clarity about funding in respect of the personalisation agenda
	Can campaign on behalf of people	Some people prefer to have support in this way	Funding often short term	
	Flexible and responsive to needs in providing support	Alzheimer's society in particular has specialist information and research internet.	Staff retention	
		Information preventative support		
		Use of volunteers		
Housing	Sheltered accommodation	Wardens visit on a regular basis	Can't always provide the appropriate accommodation at the right time	Needs to be an improved system of contingency planning
	Limited support to people in their own homes	Dependent on the needs of the people concerned "Chester Care"	Demand exceeding housing stock availability	Extra funding to meet needs
				Training for housing support staff

PURPLE/GREEN GROUP

Service	**Needs supported**	**Strengths**	**Weaknesses**	**Comments**
Social Network		Local	Misinformation	
		People who you trust	Not everyone has a social network	
		Immediate	Inconsistent	
		Know history of individual	Unlikely to refer on	
Emergency Services		Easy to contact	Unlikely to refer on	
		Quick to respond		
Internet		Easily accessible	Misinformation	
		Good information and advice	Not available to all	
		No time limit	Abuse	
		Anonymity	Stress	
General Primary Care	District nurses, Practice nurses, Podiatrists	People will attend clinic appointments	Dependant on the individual	
			Clinician's knowledge of the individual	
Mental Health Primary Care		Knowledge of Dementia	Don't respond to referrals of clients with Dementia	single point of access
		CBT knowledge	No well known - how do we access services?	Delay for clients accessing services
			No home visits	
			Opt in service	

Appendix 10

PURPLE/GREEN GROUP

Service	Needs supported	Strengths	Weaknesses	Comments
			GP appointments	Not always appropriate as clients may not attend due to cognitive impairment
			Not enough resources to assess and signpost appropriately	
General Secondary Care		Facilities and knowledge to rule out physical health problems	Environment	
			Risk - falls/wandering	
			Rely on support staff	
			Lack of 1:1 care re. nutrition	
			Quiet clients who pose no behavioural problems are ignored	
Secondary mental health		Home visits	Poor investment from Government (Cinderella service)	
		Allocated c care co-ordinator	Early onset service not available in Chester	
		Seen as an outpatient	Early onset seen by AMH teams not always appropriate	
			Have to gain support from OPMH team	
GP	Information	Variable information known to individual/carer	Variable lack of knowledge regarding Dementia	Knowledge and personal interest, dependant on individual practitioner

Appendix 10

PURPLE/GREEN GROUP

Service	Needs supported	Strengths	Weaknesses	Comments
	Advice for carers	Carer link staff. Carer noticeboard. Easily accessible	Not all GPs aware of services available	Front of house staff are effective in role. They know the clients well.
	Diagnosis	Know clients previous medical history. Exclude physical causes	Refer on to specialist services for diagnosis	Standardised approach or screening.
	Medication support	History	Can't prescribe anti-Dementia drugs therefore less knowledge?	
	What is wrong with me?	Explore all options - generalist and holistic	Reluctance to diagnose. Lack of knowledge. Indifference.	Is there a financial implication? Time restraints?
ADS	Emotional support	Independent advice 'at any stage'. Skilled staff. Everyone accepted	Not enough funding and resources. Time restraints	
	Information	National society. Easily accessible. Factsheets.	Keeping all information up-to-date in all venues	
	Raising awareness	Branch - raise awareness of what branch is doing	Alzheimer's Disease Society? Confusion regarding name.	
	Education	Accredited regional trainer (health & social care staff)	More trainers required	No longer inputting information from Social Service training.
	Advice to carers	Local knowledge is good		
Age Concern	Information and advice to carers	Independent advice.		
	Financial planning / advice	Stigma attached		

Appendix 10

PURPLE/GREEN GROUP

Service	Needs supported	Strengths	Weaknesses	Comments
	Advocacy	Confidential - people feel more confident and relaxed about approaching voluntary agencies		
Social Services	Information	Signposting to other services. Knowledge	Variable - dependent on individuals. No Access team.	
	Advice to carers			
Concern	Are middle-class ladies more likely to be referred to voluntary agencies rather than ladies living in socially deprived areas?			

Appendix 11

List of service specifications

1. Continence service- to provide suitable advice/ facilities/ equipment to deal with the service users problems.
2. Early diagnosis- support to main carer and service user prior to diagnosis when the person with Dementia may be in denial.
3. GP Service- more awareness and speedy referral on to specialists.
4. Elderly Mentally Infirm Homes- specialist care for people with Dementia and support for families in a homely setting.
5. Support for carers – to offer carers support and information and access to support services.
6. Training for carers – basic awareness, how to cope, especially in the early stages.
7. Memory concerns – information for carers, family, friends and people with Dementia including memory screening test.
8. Specialist Dementia – specialist advice, support, therapeutic intervention, on going specialist interventions, person centred.
9. Online memory testing – early detection of memory problems, improve self awareness and empowerment and breaking down stigma, useful screening and signposting.
10. National Vocational Qualification in Dementia care/ Dementia training/ end of life care. To develop staff with a range of skills, encompassing Dementia care at all National Vocational Qualification levels.
11. Social media sites – enhance level and quality of peer support/ information/ solutions for all those affected by Dementia, using social media.
12. Learning disabilities – suitable and meaningful activities.
13. Learning Disabilities – support for family carers / service users.
14. Low level advocacy- befriending service.
15. End of life care – to identify and develop care plans for patients at the end of life. To teach and train carers to support carers and patients to die in their preferred place.
16. Dedicated community service for Dementia – to provide 24 hour dedicated community service for carers and people with Dementia and professionals.

17. Housing carer’s requirements- to ensure that accommodation for both carers and person with Dementia is fit for purpose and there is a separate bedroom for the carer.

18. Extension of Intensive Home Treatment Team. Rapid assessment and support to carers and people with Dementia. Time limited support to avoid inappropriate hospital admissions and enable people to receive treatment and support in the most appropriate environment.

19. First Stop Shop – provide initial information and signposting to all those affected by Dementia and person centred approach.

20. Time out for carers – quality time either away from the person with Dementia or together.

21. Enhanced/ specialist residential and nursing care.

22. Reviewing at all levels of the Dementia pathway worthiness and targeted assessments tailored to age and stage and red flag for GP reviewing – (dedicated not virtual team).

23. More carer Support.

24. Dementia in intermediate care.

25. Medication appropriately reviewing medication.

26. Psychological support.

27. Single assessment process – Third Sector to have a shared record across all providers of services.

28. Everybody’s business – information strategy to raise awareness.

29. Learning disabilities – accommodation/ care.

30. Responding to a change in needs that may be behavioural of physical. Single Point of Access.

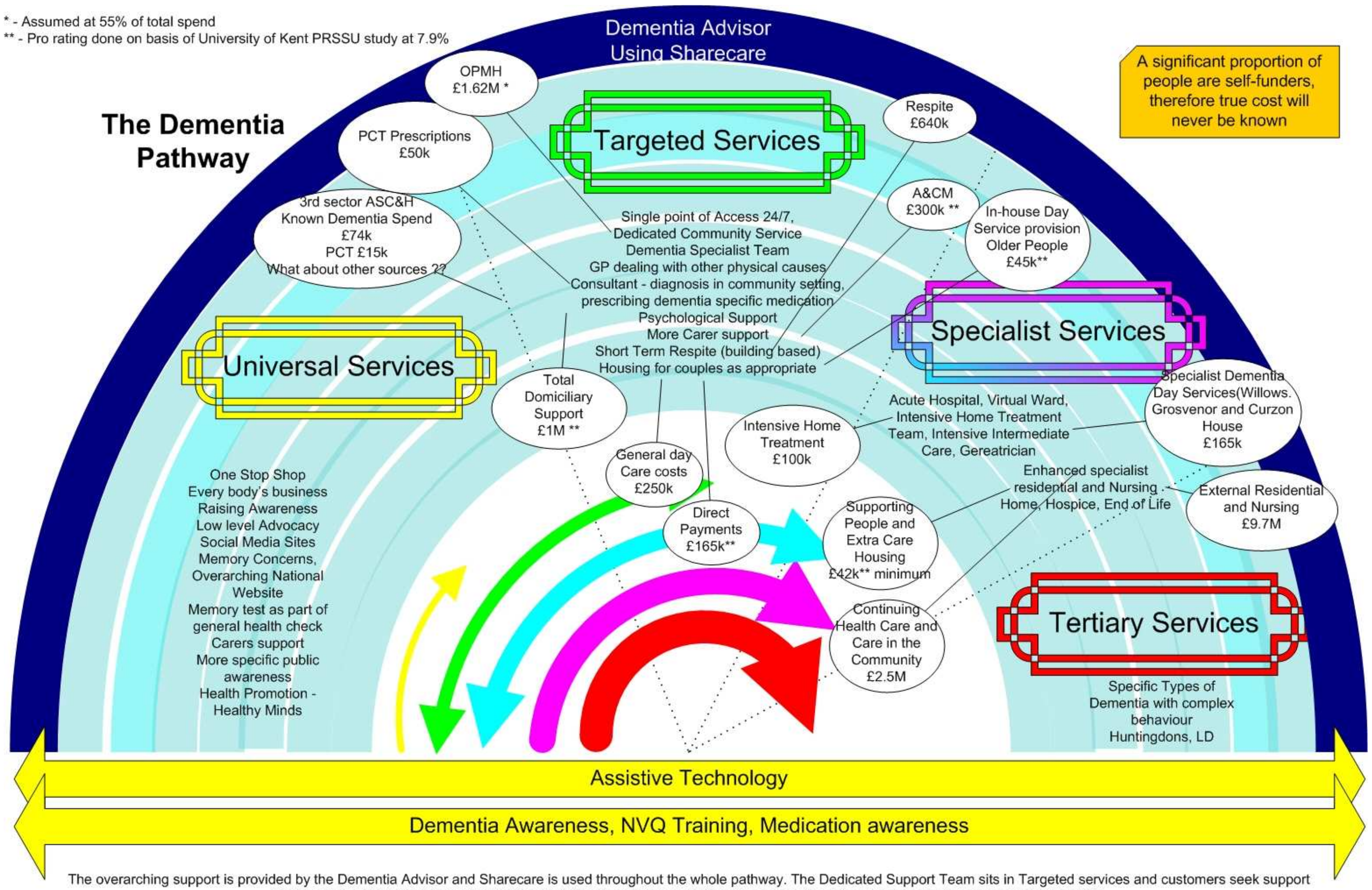
31. Assistive technology.

32. The right move – making people aware of their options regarding residential care/ funding.

33. Respite.

34. Learning disabilities – end of life care.

Appendix 12



* - Assumed at 55% of total spend

** - Pro rating done on basis of University of Kent PRSSU study at 7.9%

The Dementia Pathway

Dementia Advisor
Using Sharecare

A significant proportion of people are self-funders, therefore true cost will never be known

OPMH
£1.62M *

PCT Prescriptions
£50k

3rd sector ASC&H
Known Dementia Spend
£74k
PCT £15k
What about other sources ??

Targeted Services

Single point of Access 24/7,
Dedicated Community Service
Dementia Specialist Team
GP dealing with other physical causes
Consultant - diagnosis in community setting,
prescribing dementia specific medication
Psychological Support
More Carer support
Short Term Respite (building based)
Housing for couples as appropriate

Respite
£640k

A&CM
£300k **

In-house Day
Service provision
Older People
£45k**

Universal Services

Total
Domiciliary
Support
£1M **

General day
Care costs
£250k

Direct
Payments
£165k**

Intensive Home
Treatment
£100k

Specialist Services

Acute Hospital, Virtual Ward,
Intensive Home Treatment
Team, Intensive Intermediate
Care, Gereatrician

Specialist Dementia
Day Services(Willows.
Grosvenor and Curzon
House
£165k

Enhanced specialist
residential and Nursing
Home, Hospice, End of Life

External Residential
and Nursing
£9.7M

Supporting
People and
Extra Care
Housing
£42k** minimum

Continuing
Health Care and
Care in the
Community
£2.5M

One Stop Shop
Every body's business
Raising Awareness
Low level Advocacy
Social Media Sites
Memory Concerns,
Overarching National
Website
Memory test as part of
general health check
Carers support
More specific public
awareness
Health Promotion -
Healthy Minds

Tertiary Services

Specific Types of
Dementia with complex
behaviour
Huntingdons, LD

Assistive Technology

Dementia Awareness, NVQ Training, Medication awareness

The overarching support is provided by the Dementia Advisor and Sharecare is used throughout the whole pathway. The Dedicated Support Team sits in Targeted services and customers seek support as and when required/needed. The Dedicated Support Team also provides in-reach support to advise specialist services such as acute.

The yellow, green and pale blue lines show the movement of customers up the pathway as their support needs increase for short periods and then down the pathway to lower levels of resources. The pink and red lines show that some customers will move to high end need and remain there.

The thickness of the lines also denotes higher cost of resources.

Appendix 13

Western Cheshire Primary Care Trust
Equality Impact Assessment Template (Version 3.0)

BACKGROUND

1. The Race Relations (Amendment) Act 2000, Disability Discrimination Act 2005 and the Equality Act 2006 requires the Trust to prioritise and undertake Equality Impact Assessments on those of its existing and proposed **policies and functions (services)** that have been assessed as being **relevant** to the **general duty** of promoting equality. During initial assessments undertaken whilst developing the Primary Care Trust's Single Equality Scheme it was agreed that all policies, procedures and functions (services) would be included in the process.

ABOUT THIS TEMPLATE

2. This template guides you through the process for ensuring that the above duty is met. All completed templates must be forwarded to Andy Meadows, Head of Corporate Services and Business based at the 1829 Building. You should also retain a copy for your records which will be made available upon request, to staff, members of the public, statutory and / or inspectorate bodies.

3. You should not attempt to complete this template until you have attended training sessions on Equality & Diversity and Impact Assessments.

DEFINITIONS

4. In terms of the legislation, **relevant** means 'having implications for, or affecting, the promotion of equality'. The Primary Care Trust has broadened this to include all areas of anti-discrimination law, such that relevance refers to 'having negative implications for, or affecting people from any **equality target group** regardless of their race, ethnicity, cultural background, religion, belief, disability, gender, sexual orientation, age, employment or HIV status, or responsibilities as a carer.

5. The term **function** is intended to encompass the full range of the Primary Care Trust's duties and powers, which includes clinical and corporate services.

6. The term **policy** means the full range of formal and informal decisions made in carrying out a function or delivering a particular service. Policies may take the form of a clear written statement, or may be implicit in management decisions or "custom" and "practice". Policies may also take the form of a strategy or action plan.

7. The terms:
   a) **procedure** means any process used to deliver a function or to apply a policy.
   b) **facility** refers to any accommodation where staff are based or services are provided from.

8. A policy, procedure, function (service) or facility is relevant if it has implications for, or in any way affects the elimination of unlawful discrimination or the promotion of equality. In practice any policy, procedure or function (service) that has a direct or indirect impact on the public may be potentially relevant. This may include functions, policies, procedures or facilities relating to service delivery, policy formulation, employment and patient/public involvement.

   Some functions (services) may be less relevant but need to be included in the assessment process to provide an audit trail showing that they have been considered and identifying any evidence that supported the decision. Consideration must also be given to all policies, procedures or functions (services) carried out wholly or partly through a contractor and to those that are carried out in partnership

EVIDENCE

9. It is important that there is clear evidence for the decision on whether the policy, procedure, function (service) or facility has a high, medium or low impact. This may be through:
   a) Knowledge of e.g. the culture of a particular ethnic group
   b) Complaints
   c) Surveys
   d) Performance data
   e) Inspection / audit / assessment
   f) Anecdotal evidence

KEY POINTS FOR CONSIDERATION

10. Some key points to consider when assessing the possible impact of functions/ policies and procedures
    a) Could the policy or the way the function (service) is carried out have an adverse impact on people from equality target groups? In other words, does it put some diverse groups at a disadvantage?
    b) Could the policy or the way the function (service) is carried out have an adverse impact on relations between different groups?
    c) Is the adverse impact, if any, unavoidable? Could it be considered to be unlawful discrimination? Can it be justified by the aims and importance of the policy or function (service)? Are there other ways in which the Primary Care Trust's aims can be achieved without causing adverse impact on some diverse groups?
    d) Could taking particular measures reduce the adverse impact?
    e) Is further research or consultation necessary? Would this research or consultation be proportionate to the importance of the policy or function (service)? Is it likely to lead to a different outcome?

Appendix 13

11. **Race and Ethnicity**
    a) The provision of an interpreter for people whose first language is not English,
    b) Written communication and use of language particularly jargon or colloquialisms etc,

    c) Respect in terms of religion, belief and culture.

12. **Age**
    a) Any discriminatory employment practices regardless of age (young or old) including recruitment, personal development, promotion, entitlements and retention,
    b) Services should be provided, regardless of age (young or old), on the basis of clinical need alone.

13. **Religion, Belief and Culture**
    a) Prayer facilities for service users and staff,
    b) Dietary requirements,
    c) Gender of staff when caring for females,
    d) Respect for requests from staff to have time off for religious festivals and functions,
    e) Respect for dress codes.

14. **Disability**
    a) Reasonable steps that can be taken to accommodate the disabled persons requirements including,
       - physical access,
       - format of information,
       - time of interview or consultation event,
       - personal assistance,
       - interpreter,
       - induction loop system,
       - independent living equipment,
       - content of interview or course, etc.

    b) Steps to make reasonable adjustments to service delivery and employment practices to ensure “accessible to all”.

15. **Gender**
    a) Equal access to recruitment, personal development, promotion and retention,
    b) Childcare arrangements that do not exclude a candidate from employment and the need for flexible working,
    c) The provision of single sex facilities, toilets, wards, etc,
    d) Equality of opportunity in relation to health care for individuals irrespective of whether or not they are single divorced, separated, living together or married.

16. **Sexual orientation**
    a) Recognition and respect of individuals sexuality,
    b) Recognition of same sex relationships in respect to consent and inheritance,
    c) The maintenance of confidentiality about an individual's sexuality.

17. **Carers**
    a) Reasonable steps that can be taken to accommodate carers requirements, such as,
    - time of meetings or interviews,
    - flexible working,
    - carers' assessments.

Please Note - Section 15 should only be completed if you are assessing a function (service).

Appendix 13

Western Cheshire Primary Care Trust
Equality Impact Assessment Template (Version 3)

1. Where you work: *(Select One)*	x PCT – Commissioning Arm	☐ Provider Services Unit
	☐ Cheshire Health Agency	☐ North West Specialist Commissioning Team
	☐ Cheshire HR Service	☐ Cheshire ICT Service
2. Department:	Integrated Strategic Commissioning Team	
3. Details of person completing this form:	**Name:**	Cathy Davis
	Job Title:	Head of Mental Health and Learning Disabilities
	Email:	Cathy.Davis@wcheshirepct.nhs.uk
	Tel No:	01244 650304
4. Assessment Start Date:	22 January 2010	

5. Title of policy / function / service / project etc being assessed:	Dementia Strategy
Is the policy / function / service / project etc …*(Select One)*	☐ Existing and being reviewed, or
	☐ x a NEW development

6. What is the main purpose (aims / objectives) of this policy / function / service / project etc?

The main purpose of this strategy is to respond to the national guidance and set out a clear vision for the transformation of Dementia services in NHS Western Cheshire and Cheshire West and Chester Council. The document outlines how the commissioning arm intends to develop high quality service delivery via partnership working across Health, Social Care and Third Sector.

Formatted: Numbered + Level: 1 + Numbering Style: 1, 2, 3, … + Start at: 1 + Alignment: Left + Aligned at: 0 cm + Tab after: 0.7 cm + Indent at: 0.7 cm

7. Will patients, carers, the public or staff be affected by this policy / function / service / project etc? *(Indicate for each category)*	**Patients**	☐ x Yes	☐ No	☐ Don't Know
	Carers	☐ x Yes	☐ No	☐ Don't Know
	Public	☐ x Yes	☐ No	☐ Don't Know
	Staff	☐ x Yes	☐ No	☐ Don't Know
	If staff, how many individuals are likely to be affected?			

8.	**Have patients, carers, the public or staff been involved in the development of the policy / function / service / project etc?**	☐ x Yes	☐ No		
	If YES, who have you involved and how have they been involved?				
	A baseline report was commissioned from the Alzheimer's Society and this included postal questionnaires to professionals and carers. The Care Service Efficiency Delivery methodology recommends 20% engagement of service users and carers in the process. Five one day workshops were held between September and December 2009 and each was attended by 30-40 key stakeholders including health, social care, third sector agencies, representative carers and a service user. In between each workshop facilitators and representatives from Alzheimer's Society consulted with established carer's groups.				
9.	**In relation to Staff do you have any data on the number of people from Equality Target Groups that will be affected by this policy / function / service / project being assessed?** Data of the Primary Care Trust's Workforce, if available, is located on the Equality and Diversity section of both the Primary Care Trust's Staff Extranet and Public website (subject to declaration by members of staff)				
a)	**People from different racial & ethnic groups**	☐ x Yes	☐ No	Details:	Primary Care Trust Workforce Data (available on Equality & Diversity section of the Trust's Extranet) Cheshire West and Chester Council (CWAC) maintain workforce data records.
b)	**People of different gender (male, female, transgender)**	☐ x Yes	☐ No	Details:	Primary Care Trust and CWAC hold Workforce Data for male and female staff. No data currently collected on transgender staff
c)	**People from different religions or beliefs**	☐ x Yes	☐ No	Details:	Primary Care Trust Workforce data only includes data for recently recruited staff. No data currently on existing staff. CWAC does not currently report on this strand (existing data represents amalgamation from previous authorities, which were inconsistent in the approach).
d)	**Disabled people with:** ▪ **Physical impairments (including wheelchair users)** ▪ **Sensory impairment** ▪ **Mental illness** ▪ **Learning disabilities**	☐ Yes ☐ x Some not others ☐ Not applicable	☐ No	Details:	Primary Care Trust Workforce data only includes data for recently recruited staff. No data currently on existing staff. CWAC hold similar data.
e)	**People of different ages (children up to 18 and adults)**	☐ x Yes	☐ No	Details:	Primary Care Trust and CWAC Workforce data

f) People of various sexual orientation; lesbian, gay, bisexual	☐ x Yes	☐ No	Details:	Primary Care Trust Workforce data only includes data for recently recruited staff. No data currently on existing staff. CWAC does not currently report on this strand (existing data represents amalgamation from previous authorities, which were inconsistent in the approach).
11. In relation to <u>patients and public</u> do you have any data on the number of people from Equality Target Groups that will be affected by this policy/function/service/project being assessed? Such as Count Me In Census, Service Monitoring, National Census				
a) People from different: ▪ **Racial & ethnic groups,** ▪ **Gypsies, travellers** ▪ **Refugees and asylum seekers**	☐ Yes ☐ x Some not others ☐ Not Applicable	☐ No	Details:	Census Data Data from Office for National Statistics Service returns for inpatients services (not collected for patients treated in the community) Population Profile data extracted from the ‘Health Review’ and available on the Primary Care Trust’s public website and staff Extranet. School Census Service equality monitoring data
b) People of different gender (male, female, transgender)	☐x Yes	☐ No	Details:	As 11a above, but no data currently available for transgender patients and staff
c) People from different religions or beliefs	☐ x Yes	☐ No	Details:	As 11a above
d) Disabled people with: ▪ **Physical impairments (including wheelchair users)** ▪ **Sensory impairment** ▪ **Mental illness** ▪ **Learning disabilities**	☐ x Yes ☐ Some not others ☐ Not Applicable	☐ No	Details:	As 11a above, but data not available on impairments
e) People of different ages (children up to 18 and adults)	☐ x Yes	☐ No	Details:	As 11a above, but no ‘service’ specific data except where treated as an inpatient
f) People of various sexual orientation; lesbian, gay, bisexual	☐ Yes	☐ No	Details:	Not routinely collected as part of the assessment. CWAC uses estimates based on national research carried out by Stonewall (no accurate data available).
g) Carers (Adults & Young Carers)	☐ x Yes	☐ No	Details:	Census Data Data from Office for National Statistics
12. Are you aware of any consultation or involvement events that been held with individuals or organisations from Equality Target Groups that could				

have influence on the policy/function/service/project being assessed? (Engagement could include formal events such as face to face meetings, focus groups, questionnaires, documentation, use of website or email)				
a) People from different: ▪ **Racial & ethnic groups,** ▪ **Gypsies, travellers** ▪ **Refugees and asylum seekers**	☐ Yes	☐ No	Details:	National Dementia Strategy was consulted on prior to publication.
	☐ Some not others			
	☐ Not Applicable			
b) People of different gender (male, female, transgender)	☐ x Yes	☐ No	Details:	See section 9
c) People from different religions or beliefs	☐ x Yes	☐ No	Details:	See section 9
d) Disabled people with: ▪ **Physical impairments (inc. g wheelchair users)** ▪ **Sensory impairment** ▪ **Mental illness** ▪ **Learning disabilities**	☐ Yes	☐ No	Details:	See section 9
	☐ Some not others			
	☐ Not Applicable			
e) People of different ages (children up to 18 and adults)	☐ x Yes	☐ No	Details:	See section 9
f) People of various sexual orientation; lesbian, gay, bisexual	☐ x Yes	☐ No	Details:	See section 9
g) Carers (Adults & Young Carers)	☐ x Yes	☐ No	Details:	See section 9 (adult carers only)
h) Collective consultation, where this was open to all stakeholders including staff, patients, carers, members of the general public and partners organisations	☐ x Yes	☐ No	Details:	Baseline assessment and 5 Workshop process as described in section 9.

13. Evidence from Staff:
Do you have any evidence or reason to believe that this policy / function / service / project etc, has or could result in an adverse/negative impact on people from Equality Target Groups listed in sections 10, 11 and 12 of this form?

This includes anecdotal evidence and information from Staff involvement events, Staff Surveys, Grievances, Health & Safety, Risk, Access & Facilities Audits, Patient & Public Involvement, PEAT Reports

	Race	Disability	Gender	Age	Sexual Orient-ation	Religion / Belief	Carers	Any Other Group
I have some evidence	☐	☐	☐	☐	☐	☐	☐	☐
I have no evidence	☐x	☐x	x	☐x	☐x	☐x	☐x	☐x

Please list the evidence and / or reason below:

14. Evidence from Patients & Public:
Do you have any evidence or reason to believe that this policy/function/service/project etc, has or could result in an adverse/negative impact on people from Equality Target Groups listed in sections 10, 11 and 12 of this form?

This includes anecdotal evidence and information from Involvement Events, Forums, Patient Satisfaction Surveys, Complaints, Health & Safety, Risk, Access & Facilities Audits, Patient & Public Involvement Forum, PEAT Reports

	Race	Disability	Gender	Age	Sexual Orient-ation	Religion / Belief	Carers	Any Other Group
I have some evidence	☐	☐	☐	☐	☐	☐	☐	☐
I have no evidence	☐x	☐x	☐x	☐x	☐x	☐x	☐x	☐x

Please list the evidence and / or reason below:

Please Note – Section 15 should only be completed if you are assessing a function (service).

15. Staff training and other miscellaneous issues… N/A Strategy document

a) Have all staff attended training on Equality & Diversity within the last 2 years?	☐ Yes	☐ No	Details:	

b)	**Have all managers attended training on Equality & Diversity within the last 2 years?**	☐ Yes	☐ No	Details:	
c)	**Are you confident that these trained managers apply the criteria of the 'Two Ticks' Positive About Disabled People accreditation in all recruitment and workforce situations?**	☐ Yes	☐ No	Details:	
d)	**Have all staff attended training on Disability Awareness within the last 2 years?**	☐ Yes	☐ No	Details:	
e)	**Have all staff attended training on Deaf Awareness within the last 2 years?**	☐ Yes	☐ No	Details:	
f)	**Do all staff know how to access language interpreter and translation services?**				
	▪ **Face to face?**	☐ Yes	☐ No	Details:	
	▪ **Translation**	☐ Yes	☐ No		
	▪ **Telephone**	☐ Yes	☐ No		
g)	**Are professional language interpreters always engaged during confidential consultations (including legal meetings, care planning and reviews) with patients and carers?**	☐ Yes	☐ No	Details:	
h)	**Are professional British sign language interpreters always engaged during confidential consultations (including legal meetings, care planning and reviews) with patients and carers?**	☐ Yes	☐ No	Details:	
i)	**Do all staff know how to access and use an induction loop facility (fixed or portable)?**	☐ Yes	☐ No	Details:	
j)	**Is the building where the service is located wheelchair accessible?**	☐ Yes	☐ No	Details:	
k)	**Does the reception area have an induction loop system?**	☐ Yes	☐ No	Details:	
l)	**Does the building have a unisex wheelchair accessible "disabled" toilet?**	☐ Yes	☐ No	Details:	
m)	**Does the building have car parking spaces reserved for Blue Badge Holders?**	☐ Yes	☐ No	Details:	
n)	**Does the building have any additional facilities for disabled people such as a wheelchair, hoist, specialist bath, etc?**	☐ Yes	☐ No	Details:	

o) Does it have any other facilities for people from Equality Target Groups such are prayer and faith resources, etc?	☐ Yes	☐ No	Details:	
p) Is there anything else that has been undertaken to support equality & diversity such as guidelines, policies, etc?	☐ Yes	☐ No	Details:	

16. Who was involved?
List the people who were involved in this assessment. (Staff, staff side representatives, service users, carers, partner agencies / organisations)

Findings from the workshops have been collated into the strategy which is reporting to Departmental Management Team of CWAC and PCT Board.

17. What supporting evidence was used?
List the evidence which was used during this assessment (Including staff or service monitoring data, staff or service user satisfaction surveys, reports, etc)

A total of 1,410 questionnaires were distributed to a range of professionals with a 15% response rate and 120 questionnaires were distributed to carers with a 52.5% response rate as part of the Baseline Assessment undertaken by the Alzheimer's Society. Joint Strategic Needs Assessment and input from key stakeholders at the 5 workshops.

18. What is the Trust doing to support Equality & Diversity in relation to the policy / function / service / project?
List the evidence such as guidelines, training, etc.

Both organisations are raising the awareness of Equality and Diversity.

19. Action Plan – List all actions (large and small) that have been identified during the assessment and include a named person and date for completion.

Action	**Name Lead**	**Date to be Achieved**
Future actions to be determined following reporting to the DMT and PCT Board.		

20. Following Equality Impact Assessment, what is your assessment?

Have you identified any issues that you consider could have an adverse/negative impact on people from Equality Target Groups?	☐ Yes	☐ xNo

If ***NO*** you can introduce (if new) or continue to use (if existing) the policy / function / service / project etc

Appendix 13

If ***YES*** then use the Risk Rating Matrix to assess the level of risk associated to the policy / function / service / project

IMPACT (if the incidence were to occur) ↓		**LIKELIHOOD (of the incidence occurring or being repeated)** →				
		Remote	**Possible** (20% chance)	**Likely** (60% chance)	**Highly Likely** (90% Chance)	**Certain**
	Score	1	2	3	4	5
Insignificant	1	**1 (GREEN)**	**2 (GREEN)**	**3 (GREEN)**	**4 (GREEN)**	**5 (GREEN)**
Minor	2	**2 (GREEN)**	**4 (GREEN)**	**6 (AMBER)**	**8 (AMBER)**	**10 (AMBER)**
Significant	3	**3 (GREEN)**	**6 (AMBER)**	**9 (AMBER)**	**12 (AMBER)**	**15 (AMBER)**
Serious	4	**4 (GREEN)**	**8 (AMBER)**	**12 (AMBER)**	**16 (RED)**	**20 (RED)**
Catastrophic	5	**5 (RED)**	**10 (RED)**	**15 (RED)**	**20 (RED)**	**25 (RED)**

INSERT YOUR RISK SCORE HERE	
	SCORE
IMPACT (I)	
LIKELIHOOD (L)	
OVERALL SCORE (I x L)	
GREEN / AMBER / RED	

YOUR RISK ASSESSMENT SCORE WILL DICTATE WHAT YOU NEED TO DO WITH THE POLICY / FUNCTION / SERVICE / PROJECT etc

SCORE	**STATUS**	**ACTION**
GREEN	**New and existing**	You can introduce (if new) or continue to use (if existing) the policy / function / service / project etc whilst undertaking the actions listed in Section 18
AMBER	**New**	Only introduce the policy/function/service/project etc after undertaking the actions listed in Section 18.
	Existing	Contact the Equality & Diversity Advisor to discuss the priorities of further actions listed in the Section 18
RED	**New**	Do not introduce this measure until further investigation has been completed. Contact the Equality & Diversity Advisor to discuss further actions
	Existing	Contact the Equality & Diversity Advisor immediately to discuss the priorities

21. Monitoring and Review of this policy / function / service / function etc

a) Who will be responsible for monitoring this policy / function / service / project etc?

Name:	**Keith Evans**
Job Title:	**Head of Integrated Strategic Commissioning- Adults (Interim)**

	Email:	**Keith.Evans@cheshirewestandchester.gov.uk**
	Tel No:	**01244 972990**
b)	**Please name the Committee / Sub-Committee that will receive the report for monitoring this policy / function / service / project etc?**	
	DMT and PCT Board.	
c)	**When will this policy / function / service / project etc be reviewed?**	
	Deadline for completion of Dementia Strategy is 31 March 2010.	
d)	**Who will be responsible for coordinating the review of this policy / function / service / project etc?**	
	Name:	**Cathy Davis**
	Job Title:	**Head of Mental Health and Learning Disabilities**
	Email:	**Cathy.Davis@wcheshirepct.nhs.uk**
	Tel No:	**01244 650304**

Please return the completed assessment to the Equality & Diversity Lead:-
Andy Meadows, Head of Corporate Service & Business, Western Cheshire Primary Care Trust, 1829 Building,
Countess of Chester Health Park, Liverpool Road, Chester, CH2 1HL
Email: andy.meadows@wcheshirepct.nhs.uk Tel: 01244 650407

Appendix 13

THIS SECTION IS FOR COMPLETION BY THE PRIMARY CARE TRUST'S EQUALITY & DIVERSITY LEAD / EQUALITY & DIVERSITY ADVISOR ONLY		
Title of policy / function / service / project etc being assessed		
Date policy / function / service / project etc completed		
SUMMARY OF OUTCOME OF THIS IMPACT ASSESSMENT		
Was any adverse impact found?	☐ Yes	☐ No
If YES, what was the level of risk identified using the Trusts Risk Assessment Toolkit	☐ Green	
	☐ Amber	
	☐ Red	
Action Required		
Officer undertaking the review of this Impact Assessment?		
	Name:	
	Job Title:	
	Email:	
	Tel No:	
	Date:	
Date when compliance against Equality Impact Assessment was monitored		