Older People [Dementia Care Long Term Placements] Commissioning Strategy 2013- 2018

Contents:

	Page
Introduction	3
Section 1 Legislation, National Guidance and Best Practice	5
Section 2 What do we know?	6
Section 3 What we know now about the current and future dementia population	14
Section 4 Views of Stakeholders	19
Section 5 The Issues	21
Section 6 What we will do	24
Section 7 Next Steps	28
Section 8 Conclusion	29
Acknowledgements	29
Section 9 Appendix	30

Introduction

This strategy document sets out our vision for long term care services for people living with dementia in Flintshire over the next five years. It's focus is primarily residential care services but it recognises that much work is needed to improve the quality of life for people living with dementia in all settings. We hope that through this document we will significantly change people's understanding and expectations of what "good dementia care" looks like and more importantly feels like for those who use dementia services in the future.

> ***What is Dementia****? - Dementia is a debilitating condition (and not a part of natural ageing) which describes a collection of symptoms, including a decline in memory, reasoning and communication skills and a gradual loss of skills needed to carry out daily activities – includes Alzheimer's and a range of other conditions such as vascular dementia. (Alzheimer's Society 2007)*

Life with dementia is still worth living. None of us would choose to experience dementia. Receiving a diagnosis often creates feelings of shock, anger, fear, distress or denial, however many people who experience dementia go on to do amazing and fulfilling things in their lives so it is really important to recognise that Dementia is only a part of a person not the whole.

Life should be a passionate experience; full of amazing people, feelings, events, moments and gifts to treasure this should not stop because you are diagnosed with Dementia. In Flintshire we want people living with dementia to be able to live fulfilled and meaningful lives, to feel safe and be supported in their communities and wherever the "*dementia road* "may take them to be sure there will be care and support services flexible enough to meet their unique wishes and needs.

The overarching objective of this strategy is to ensure that people living with dementia have access to high quality person centred dementia care in the most appropriate settings to meet their needs and that there is sufficient provision available within Flintshire's boundaries.

Ideally we would want this to be a joint commissioning strategy with our partners in Health (Betsi Cadwalader University Health Board). Given that the footprint of BCUHB stretches across the whole of North Wales we recognise that we will need to work towards this goal largely through a regional collaborative approach, involving Social Services colleagues in the other five Local Authorities.

Currently BCUHB has prioritised the development of a dementia strategy to focus on raising awareness of dementia and improving patients experience on inpatient wards in hospitals. Over time this strategy will be rolled out to include all NHS staff including those working in primary care and community settings. Our Vision for the future is one where Health and Social Care services work

together in an integrated way adding value to each other and where all services either those directly provided or commissioned by our respective organisations are tailored to meet the individual needs of people affected by dementia. Carers and families supporting people living with dementia told us very clearly that this must be our priority.

"*The lack of communication between departments was stressful and frustrating for me as a carer, I felt that no one understood or cared about our situation*"
(Flintshire Carer from Listening Event October 2013)

We recognise there will come a point when some people with dementia will no longer be able to remain safe at home owing to their increased need for specialist care. We know from a recent study that the prevalence of the condition among people in residential care homes has increased from 56% of residents twenty years ago to 70% today (CIPH 2013).

It is our intention that these people should have a choice of specialist dementia care homes that are close to family and their local communities. At present in Flintshire we know that we do not have enough specialist care home places available in particular EMI Nursing provision. This has meant that many people have had to move outside of Flintshire and family and friends have to travel into neighbouring Authorities to keep in touch .We want this to change.

We want to be proud of what we commission and therefore our vision is that our providers will deliver person -centred dementia care that achieves real outcomes for the people they support. We will only purchase from those Care Home providers who adopt a proven model which shows that people with dementia matter and supports them to have a quality of life.

Section 1 - Legislation, National Guidance and Best Practice

1.1. Unfortunately there is little legislation and guidance that is specific to providing dementia care within Care Homes. However, there are a number of research papers that describe best practice and these have been used to inform and shape this strategy:

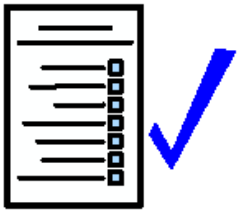
- " A National Dementia Vision for Wales " National Assembly for Wales 2011
- The Social Care and Wellbeing (Wales) Bill 214 -16
- David Sheard 2013 " Steering " culture change matters in dementia care homes – a Commissioning briefing
- David Sheard 2009 " Feelings Matter Most"
- " Progress in Personalisation for People with dementia" (Adams, Routledge & Sanderson 2012)
- Stirling University – The Dementia Care centre – a number of design guides.
- University of Bradford 'Dementia Care Mapping' (Kitwood and Bedin)
- " My Home Life " (Best practice in Care Homes) www.myhomelife.org.uk
- "Involving families in care homes": a relationship centred approach to dementia care. 142. Jessica Kingsley Publishers.(Woods 2007)
- "Changes in the quality of life of people with dementia living in care homes." Alzheimer Disease & Associated Disorders 23 (3) 285-290 Hoe et al 2009
- Nelis et al (2011)" Awareness of social and emotional functioning in people with early-stage dementia and implications for carers." Aging and Mental Health 15,(8), 961-969

The key message from these documents is that people with dementia should be valued as individual people and receive support to take part in life by staff who truly understand them and create positive opportunities for engagement and communication on a daily basis. It recommends that EMI Care Home environments should not be designed as mini hospitals or based on a "Hotel" style concept but rather they should feel warm, homely, comfortable places where design features are used to promote independence and safety. A place where families feel welcome and relationships flourish.

Section 2- What do we know?

2.1 Headlines

- Currently Flintshire has 7 independent EMI residential homes offering a total of 172 placements and two Local Authority Homes with small specialist EMI units offering 16 placements. So a total of **188 Emi Residential placements** in Flintshire.
- Flintshire has only **one EMI Nursing home within its boundaries offering a total of 23 placements.**
- 69 people living with dementia have had to move outside Flintshire for EMI Nursing care provision
- We also know that the quality of EMI residential dementia care services in the Independent sector do not consistently deliver good person centred care to their residents. Four out of the seven independent sector EMI residential homes have become "services of concern" within the last 2 years and had embargo's in place to prevent further admissions and one EMI Nursing home has been closed down.
- Our annual spend on EMI Nursing and Residential services is in excess of £4.4 million



Key Messages:

- There are not enough EMI Nursing Home placements within Flintshire boundaries.
- The quality of person centred care in some of our independent EMI Residential homes needs to improve.

2.1 – What services currently exist to support people living with dementia in Flintshire

2.1.1 Community – Based Services

- We have changed our in -house homecare service to support people with dementia to live at home. Rather than just have care staff visit at set times each day to complete tasks and then go on to the next call we have made the service more responsive to the persons needs on the day, and tailoring support visits around the person and their circumstances. We have even renamed our Domiciliary Dementia Service **"**Living Well", so everyone is clear about it's purpose.

- We have appointed 3 Dementia support workers to work closely with families when people with Dementia are admitted to hospital so we can ensure they get the help they need during their stay and return home as quickly as possible.

- We have opened the 'Old Brewery' Resource centre as a drop in service specifically for younger people with dementia and their families.

- We promote the use of Direct Payments, so that people living with dementia and their carers can have an opportunity to directly purchase their own care and support and arrange it to suit their individual circumstances.

- We seek to promote the well being of people with dementia through our Flintshire Sounds Project. A weekly singing group for people living with dementia, their carers, families and friends.

- We promote the use of telecare assistive technology that will help people remain independent in both their own homes and in residential settings.

A case study to show how telecare has helped a person with dementia remain in a familiar environment.

Mrs L has a diagnosis of dementia and osteoporosis and has previously fractured her leg. Mrs L lives on the 3rd floor in a long stay setting. The Home Manager raised concern for Mrs L when she started wandering down the stairs at night. A telecare assessment was undertaken and identified the need for the following equipment; property exit sensor, carer alert, pager receiver, transmitter mains power and pager charging station. All the equipment was installed on the same day which meant that every time during the night Mrs L left her room staff were alerted so they could reassure and support her to return to her room. Mrs L was therefore able to remain in the environment she was familiar which was important.

- We estimate that of the 556 telecare assessments undertaken last year 85% of people had some form of dementia related illness. The type of Telecare equipment issued ranged from the Intellilink alarm, smoke detectors, impact falls detector, bed exit sensors, property exit sensors, movement detectors (PIR), automatic pill dispensers, carer alerts and some GPS safer walking devices. Social Workers in older people services also use 'Just Checking equipment' as part of their assessments. This monitoring system enables staff to build up a picture of an individual's daily routines and behaviours so that we can ensure that domiciliary services are made available to support that individual when they need it most. We are actively working to increase the current assessment capacity in this service by 50% to enable more individuals to benefit from this type of support over the next 5 years.

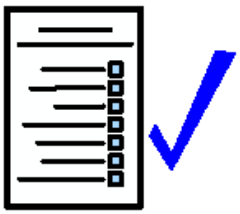
- We have opened the first extra care facility in Wales to offer specially designed apartments for people living with Dementia at Llys Jasmine in Mold. This is an exciting new build development in partnership with

Wales and West Housing Association and will offer a real alternative to people who do not wish to move into long term residential care. We would like to develop a further two extra care schemes within Flintshire and consider providing further designated apartments within them for people with dementia. Building on our learning from Llys Jasmine and Llys Eleanor ,our existing Extra care facilities, we will seek to engage with our independent sector domiciliary providers to develop a "Living Well " model of support services for any future schemes.

2.1.2 Local Authority long stay provisions.

- The Local Authority has two small EMI facilities within its homes in Buckley and Flint. Both offer respite care to enable carers and families to have a short break. The Local Authority homes also provide day care for people with dementia and host a Saturday drop-in service for people with dementia in conjunction with NEWCIS (North East Carers Information Service).

- Our Local Authority Homes have recently entered into a partnership with 'My Home Life Wales', which is an acclaimed best practice model of person-centred care. They are helping us to develop practices that that puts relationships, families and carers at the heart of service delivery.



Key Messages:

- Our goal is to keep people with dementia at home for as long as possible.
- Our 'Living Well Home Care Service' considered best practice is limited in capacity. We need to roll out a similar model of person-centred dementia care across the Independent sector domiciliary market.
- We want to increase the use of Telecare in the community and long stay settings by 50% over the next five years.

2.2 – Current Commissioning Activity

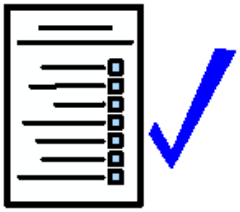
- As a major commissioner of dementia care the Local Authority has the potential to influence and shape the independent sector market. Currently all residential placements in Flintshire are "spot" purchased the only exception to this is a small number of respite places that are block purchased on an annual basis to support carers.

- There are currently 217 EMI residential places available in Flintshire boundaries (including 16 places in Local Authority Homes) and we commission 188 (87%) of these. There are only 23 EMI Nursing places

within Flintshire boundaries of which we currently commission 5 (22%) of these. BCU Health Board commission a further 10 places for people from Flintshire with Continuing Health Care needs. So within Flintshire boundaries the Local Authority is the lead commissioner for EMI residential care places but the BCU Health Board has become the lead commissioner for EMI Nursing places.

- As a result of the shortfall we both have look out of county to meet the EMI Nursing needs of people with dementia. On 1st October 2013 Flintshire were commissioning 33 EMI Nursing placements out of county whilst BCU Health Board were commissioning 36 EMI Nursing placements for Flintshire residents out of county.

- At present there are no plans to build new EMI Nursing Homes in Flintshire to increase the number of placements. Any further reduction in placements would be extremely dangerous.



Key Messages:

- We do not want people with dementia to have to move out of Flintshire to have their nursing needs met.

2.2 -How much does it cost

2.2.1 Independent Sector fee levels

Our current weekly expenditure on commissioned EMI (Residential and Nursing) provision is £83,260.38. Our commissioning approach has been to seek out quality services that offer value for money and maintain quality.

The minimum baseline fee for a contracted bed per week for EMI Nursing is £529.69 (minus Health Board contribution), this is a regional fee. For more details see appendix 9a.

Commissioner	EMI Residential			EMI Nursing			
	No.	Weekly Fee	£ Week	No.	Weekly Fee	£ Week	Total Provision
FCC	128	493.22	£ 63,132.16	38	529.69	£20,128.22	
BCUHB (FNC)	00	000000	000000000	38	120.56	£4,581	
BCUHB (CHC)	00	000000	000000000	46	626.26	£28,807.96	
TOTAL			**£ 63,132.16**			**£53,517.18**	**£ 170,196.52**

2.2.2 Unit costs for in – house residential care

Work is currently ongoing to establish a clear picture of unit costs in our two in-house homes. This will inform future decisions about the viability of one or both of these homes becoming re- registered as an EMI Residential Home. Early indications however suggest that this option may not achieve best value for money for the Authority at this time.

2.3 -What do we know about the quality of EMI care home provision

To establish the level of quality of our current EMI care home provision in Flintshire we considered a number of different sources:

- Tracking the journey into EMI homes
- Progress for Providers Self- Assessment
- Care Checker
- Complaints and POVAs
- Survey to obtain the views on choice, care and community for people with dementia in Flintshire care homes.
- Findings from Contract Monitoring Questionnaires (Family/ Representative request)

2.3.1 Tracking the journey into EMI homes

We tracked a snapshot of Service requests that were presented to our Community Care Panel during 2012 and 2013. We looked at the outcomes for service users during the months of May and June during these two years. A total of 555 cases were considered by the Community Care Panel of which **105** were agreed as requiring long term placements. This number included **18** placements that were made directly from a hospital setting directly into a long term care placement for individuals with dementia

We then considered the experience of those 18 individuals admitted to long term Emi placements in more detail and found that:

a. **27% (5)** saw an escalation in the level of care needed following hospital admission and as a result were not discharged back to their previous long term Emi residential placement but transferred to an Emi nursing placement.

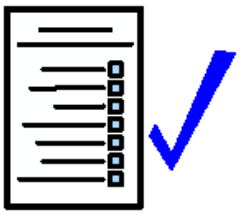
b. **27% (5)** of individuals who previously accessed significant" Community care packages were discharged directly into an Emi residential care placements.

c. **42% (8)** of individuals who had previously accessed a low level community care package or received no formal support services at all were discharged from hospital into Emi residential care placements (and all but one of these individuals had been supported at home by a partner living in the same household or a family carer providing frequent visits prior to hospital admission.)

In **68% (13)** of cases where there had previously been a community care package in place **(b and c above)** the family carer identified that the need for a hospital admission arose as a result of the escalation in confusion and subsequent "challenging behaviour" presented by the individual with dementia. Generally there was evidence that a diagnosis of common clinical conditions such as UTI or chest infections had also been made by the GP or on admission to hospital Family carers also identified 'sleeplessness at night time' as the significant factor in either precipitating the current crisis or influencing the decision to relinquish their caring role at that point .

In Summary:
This mapping exercise appears to confirm that hospital admission is often a trigger for long term care placement for individuals with dementia and is also likely to result in an increased level of support being required for those already in an EMI placement. For informal carers the issue of being able to access the right kind of health and social care services at the right time in the community for the person with dementia when physical health needs exacerbate cognitive issues is critical. Moreover this exercise illustrates the importance of recognising informal carers own needs for additional support sooner if they are to sustain their caring role for longer.

Key Messages:



- Health and Social Services need to work more effectively together in the community to prevent unnecessary hospital admissions and maintain people with dementia in their own homes.
- Carers of people with dementia need timely support from professionals who really understand dementia and can offer a flexible response to their individual situations.

2.3.2 Progress for Providers Self-Assessment Tool

We asked a random sample of Flintshire EMI Residential Homes (in – house and independent) to complete a recognised self assessment tool – 'Progress for Providers' to enable us to establish a benchmark on the quality of current provision in Flintshire. There were significant variations in the assessment scores which reinforces the premise that there is no consensus about what 'good' dementia care looks like. The majority of providers rated themselves as delivering person centred care but many recognised significant areas for further development. This exercise clearly indicated the need for further training opportunities particularly in relation to leadership, communication and utilising life stories in day to day practice.

2.3.3 Care Checker

We commissioned 'Care Checker', a listening organisation to meet with residents and families and provide feedback on people's experience of living in a residential home. In total sixteen family members across 3 homes participated from whom a wealth of quality feedback was obtained (refer to appendix 9b 1.7). Three key messages we gathered from this work was:-

- The importance and value of involving carers, families and friends.
- That continuity of support is the most important thing in judging whether the home provides a quality service and centres on truly knowing the person and family.
- That families need to know what 'good' dementia care looks like , it should be more than just 'bed and board'

2.3.4 Complaints and POVAs

From April 2012 to March 2013 we received 4 complaints relating to an EMI nursing home provider. The nature of these complaints related to poor quality of care, poor communication with families and disrespectful staff attitude towards residents. All complaints were connected with one particular provider who has since been decommissioned.

In relation to POVA (Protection of Vulnerable Adults) activity for period January 2012 to December 2012 across EMI providers there were 11 POVAs which were recorded as 'upheld'. The 11 were spread across 4 homes and were classified as neglect (4), physical assault (1), emotional (3) and sexual abuse (3). The range of responses taken has included action plans and close monitoring, policy updates, extra training and disciplinary action. The reoccurring theme from all these reports point to an inexperienced workforce that lack the skills necessary to deal with complex and at times challenging needs of people as they progress along the '*dementia road*'.

2.3.5 Contract Monitoring Reports

The findings from Contract Monitoring Questionnaires (Family/ Representative request) and "Corrective Action Plans" developed with providers identified the following themes:

- Staff need more training with a specific focus on "communication" and "person centred care planning ".not simply " dementia awareness "
- Lack of involvement of family members and a need to encourage their contribution to life stories and daily routines.
- Greater appreciation and care of people's personal possessions including clothes, dentures and hearing aids etc is needed. .
- Greater attention to resident's personal hygiene and attire.
- Clear strategies to ensure people are meaningfully occupied and involved in the daily routine of the Home are essential.
- More use of calming, sensory and therapeutic interventions for those people in the end stage of dementia.
- Better choice of meals and promotion of meal times as a social occasion and not just a task to be completed by staff is needed.

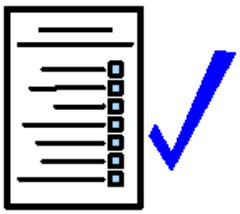
- Move away from institutional routines such as set bedtimes and “bath days” and evidenced individualised care planning and person centred record keeping.

2.3.6 Survey to obtain the views on choice, care and community for people with dementia in Flintshire care homes (refer to Appendix 9b 1.4)

In total **32** surveys were returned. Even though our numbers are small the findings and conclusions are in the main in line with the national research undertaken by the Alzheimer’s Society in 2013

- Generally family members felt the quality of life of people with dementia in Flintshire care homes was positive.

- When the different aspects of care and support were considered individually aspects that received poorer ratings were; opportunities to get involved in activities, opportunities to socialise, support to remain independent and active and access to health care services.



Key Messages:

- There are significant variations in the quality of dementia care services in Care home settings within Flintshire and no clear consensus on what ‘good’ dementia care should look like or the outcomes that should be achieved.

Section 3 - What we know now about the current and future dementia population

3.1 Older People and Dementia

- The number of older people in North Wales is rising rapidly; the 65+ age group is predicted to increase by 60% between 2008 and 2033. The population of those aged 85+ is expected to double by 2033.

- In 2012 there were 1,806 people aged 65 and over with dementia in Flintshire, this is projected to increase to 1,975 by 2015, which means there will be 169 more people will dementia. However such projections should be considered cautiously. A very recent study which gained media coverage (Mental Health today news 10-16 July 2013) has suggested that the prevalence of dementia is falling in the UK. The study undertaken by Cambridge Institute of public health (CIPH) found that applying prevalence from 20 years ago it was expected that 8.3% (884,000) people aged over 65 would have the condition in fact the study identified a lower prevalence of 6.5%, a reduction of nearly a quarter.

3.1.1 How many more EMI placements will we need in the future?

- It is very difficult to quantify how many placements we will need in the future with any certainty. We do not know how many people are living with dementia in Flintshire today due to the 'diagnosis gap'[1] and only 38.5% of people with dementia in Wales have had a formal diagnosis.

- As we are successfully supporting people to live in their own homes for longer the cohort of people now in need of residential /nursing home care has changed. People are much older with more complex needs such as dementia. This is evident from our tracking of bed vacancies in all approved homes in Flintshire from July 2011 to January 2013. We found that there were vacancies in general nursing homes but not in EMI nursing homes (see graph appendix 9c). Therefore, we either need to remodel existing provision to respond the growing numbers with complex needs such as dementia or develop new provision.

    - As of 28th January 2013 there were 118 older people assessed by Flintshire Social Services as needing either a General Nursing or EMI Nursing placements, with an average age of 85. The average length of stay in a Nursing home in 2012 was 1.9 years (range 2 months – 7 years / median 1.3 years) this compares to an average of 2.7 years in 2005.

    - To work out how many more beds we need we believe our best guess is to focus on the 85+ group with dementia, looking at what we know about current spread of service uptake on one given day and

[1] *The difference between those expected to have dementia in Flintshire and those that actually feature on dementia lists known to ourselves and Health*

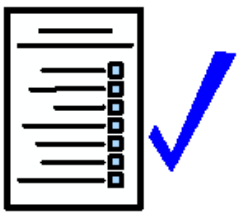
the future projections for people with dementia aged over 85 in Flintshire [2], see table below:

People with dementia 85+	2013	2015	2020
Projected number in Flintshire	787	845	1,014
Known to Social Services living in the Community	262 (33%)	279 (33%)	335 (33%)
Living in Long stay setting (funded by SS / Health)	331 (42%)	355 (42%)	426 (42%)
Unknown to SS (e.g. living at home alone/ supported by carers or self funders etc)	194 (25%)	212 (25%)	254 (25%)

Based on this approach we estimate that we will at least **need 24 more long term places by 2015 and 95 by 2020**. This attempt to forecast how many additional beds will be required in the future cannot be an exact science as there are many variables, such as assuming that we are able to maintain the status quo in terms of how well we support people with dementia to remain living at home.

People with dementia over 65 +	2013	2015	2020
Projected number in Flintshire	1,859	1,975	2,343
Known to Social Services living at home	521 (28%)	553 (28%)	656 (28%)

- We estimate that we will be supporting at least **32 more people with dementia in the community by 2015 and 135 more people by 2020**



Key Messages:

- The number of people with dementia is increasing.
- We estimate that we will be supporting at least 135 more people with dementia aged 65 and over by 2020.(based on current projections)
- We estimate that we will need at least **95 more long term places by 2020.**

[2] Daffodilcymru

3.2 Learning Disability and Dementia

- The advances in medical and social care have increased life expectancy for people with learning disabilities. Therefore we are expecting that the future number who will develop age related frailties and illnesses such as dementia will increase.

- The number of people in Flintshire with a moderate to severe learning disability and aged 65 and over is predicted to increase by 14 % from 2011 to 2015 and by 42% from 2011 to 2030.[3] We know that currently there are **12** people aged 50 and over with dementia and **over 12** people are being assessed for dementia. There are **24** people aged 50 or over still at home with their family. We also know that there are 70 people known to our service with Downs Syndrome. With this diagnosis comes a higher incidence of early onset dementia

3.3 Younger Onset Dementia

- The number projected to have early onset dementia (under 65) in 2016 is 41 which is the same figure for 2013. We have specialist service provision for people who have early onset dementias (i.e. under 65 years) in the community. We do however have a service gap in age appropriate long term placements for people with early onset dementia.

3.4 People with Hearing loss and Dementia

- There is strong evidence of a link between hearing loss and dementia. People with mild hearing loss have nearly twice the chance of going on to develop dementia as people without any hearing loss. The risk increases to threefold for people with moderate hearing loss and fivefold for those with severe hearing loss (Lin, FR et al 2011 cited in Joining Up)

3.5 Black & Minority Ethnic (BME) and Dementia

- From the Census 2011, the BME population makes up 1.5% of the Flintshire population, this compares to 0.8% from the census 2001. The BME population has a higher percentage of children than the 'White' population but a much lower proportion of older people. The number of BME people aged 85 and over in Flintshire is in single figures.

- Overall, the proportion of BME people affected by dementia is broadly the same as that found among white people. A research briefing paper by SCIE[4] identified some keys messages for us as service providers and commissioners, namely that BME people are under represented in dementia services owing to lower levels of awareness and the existence of stigma in their communities. Staff working in dementia services require training on how to give culturally acceptable care and support to BME people with dementia. Ensuring personalised approaches to services, and

[3] Daffodil Cymru website projecting future social care needs.
[4] SCIE Black and minority ethnic people with dementia and their access to support and services

greater attention being paid to the diversity and complexity that exists within the life stories of people with dementia.

3.6 Welsh Language and Dementia

- The More than Just Words Strategic Framework outlines the Welsh Governments intention to prioritise Welsh language services for people who are vulnerable. Older people with dementia are highlighted within the document as a priority group requiring welsh language services as an integral part of their care. The Welsh Government asserts that services delivered in welsh should be 'actively offered' to people suffering with dementia. We know from the census in 2011 that 13% of the Flintshire population speaks welsh. In relation to the numbers of older people who speak welsh. It is of note that 19.1% of people aged 85 and over speak welsh.

3.7 Carers of people with dementia in Flintshire.

- Focussing on maintaining independent living for people with dementia goes ‘hand in hand’ with support to carers. Growth in numbers of people with dementia implies an increase in the number of carers needed in the future. Caring for a person with dementia can be difficult as the intensity of caring required increases as the illness develops. Many carers are unpaid family members, whose own health and well being will be affected. Our changing lifestyles, smaller families, relationship breakdowns, longer period to retirement and family migration can only mean that the availability of carers will be less in the future with a resultant shift of responsibility to the statutory sector and a further pressure on diminishing resources. If carers are properly supported they can care for longer. It has been found that if carers are supported and receive counselling at the point of diagnosis a care home placement can be prevented in 28%.of cases. [5] A recent report[6] from the Carers Trust has found that carers of people with dementia are not getting the support and advice they desperately need. For example many carers, particularly those caring for someone in the later stages of the illness felt ill equipped to deal with more challenging behaviours and communication issues. More than 68% of those surveyed said they had not received the training or advice they needed on this subject.

- Our Commissioning Strategy for Carers 2012 -2015 sets out how we support carers in Flintshire. All carers have access to a range of generic carer services (carers fund, breaks, information and emotional support etc) and more specifically; a long term condition support group facilitated by NEWCIS (North East Wales Information Service) a Saturday respite service and bespoke training opportunities facilitated by NEWCIS in conjunction with Flintshire Alzheimer’s Society.

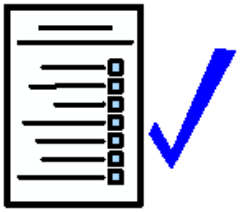
- In 2012 NEWCIS received 1,260 new referrals and of this over 60% were from carers of people with memory problems or a diagnosis with dementia.

[5] National Carers Strategy - UK
[6] The Carers Trust – A road less rocky – supporting people with dementia

There are 4,120 carers registered on the NEWCIS database caring for people with multiple and complex health care needs.

Claire Sullivan manager of NEWCIS said:

'*it is extremely sad and worrying that dementia is always the last condition to be diagnosed for older people'*

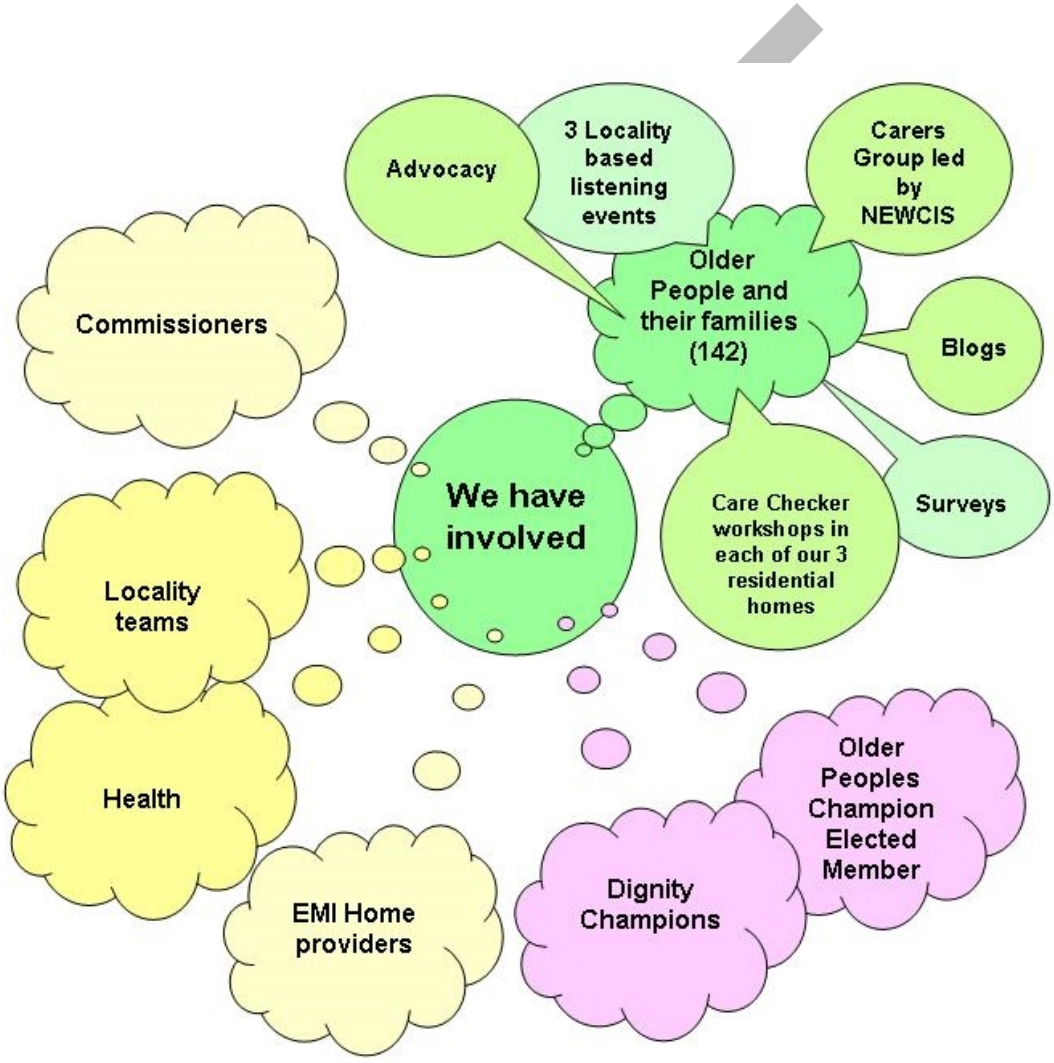


Key Messages:

- Carers should expect more than just 'bed and board' from EMI homes.
- Carers caring for a person with dementia at home need night time support.

Section 4 – Views of Stakeholders

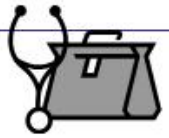
We were overwhelmed with the response from all stakeholders which clearly demonstrated how passionately people feel about this area. The detail of what people said can be found in appendix 9b. We have summarised this in two illustrations that follow. Our first illustration depicts 'who' was involved.



The second illustration which features on the next page is 'what they said' along the ***Dementia Road***.

Being diagnosed

- Early diagnosis & GP screening
- Local specialist services
- Timely information and advice for families/ carers



The dementia progresses, declining capacity & mobility; Continence, health and behaviour problems

- Informed social workers
- Informed & responsive G.Ps
- Information & advice for families / carers to help them to continue caring & deal with Progressive changes
- Prompt access to services & equipment like telecare, adaptations, continence supplies
- Timely input from Community Psychiatric Nurses

Living in a care home - People & approach

- Strong leadership; friendly & welcoming staff
- Open visiting policy
- Adopt best practice in person centred dementia care, all staff trained in the approach
- "Life Stories" & staff who can translate these into daily practice
- Families actively involved - see Care Checker feedback
- Everyone's responsibility, including visiting families to support residents to stay active e.g. in running of the home, social activities
- Opportunities to go on outings and take part in activities
- Residents supported to keep links to their community
- Care provided in the preferred language
- Involvement of young people & volunteers
- People can remain in the home as the illness progresses

D E M E N T I A R O A D

Living at home with dementia

- Carers treated as equal partners by all agencies
- Named point of contact for family
- Good communication between all agencies
- Quality support at home e.g. Living Well
- Consistency in paid carers
- Advice & support to carers
- Respite in own home
- Dementia friendly communities / activities with volunteers who have understanding e.g. luncheon clubs, dementia café, memory support friends, young people
- Community services e.g. chiropody, handyman

There might be a time in hospital

- Number of moves in hospital kept to a minimum
- Hospital staff trained in dementia
- Effective and timely discharges, good planning with families, carers and care homes

Deciding about long long term care

- Support at home for as long as possible, including care at night
- good planning for timely moves, get it right first time
- Informed choice – access to inspection reports,
- Approved Provider list, alternative like Extra Care
- People & families know what "good dementia care" looks like
- Advice & support from people who understand dementia and know the person & family

Living in a care home – the environment

- In Flintshire
- Clean and odour free
- Appropriately designed and decorated for people with dementia
- Space to wander indoors and outside
  (I like to walk the dog with my granddad)
- The Home makes use of telecare

Living in a care home – links with community based services and Home providers

- Timely "in reach" from key community based services to prevent unnecessary hospital admissions or move to other home e.g. GPs, CPNs, OTs, Social workers
- Responsive out of hours service
- Opportunity for Home providers to meet to share best practice

Section 5 - The Issues

Demographics

- **The numbers of people with dementia in Flintshire** is projected to increase by 26%[7] from 2013 to 2020. So it is critical that all services are geared up to respond to this increase in need.

Care Homes

- **The acute shortage of EMI Nursing Home placements** in Flintshire and an over reliance on out of county provision.

- **The quality of existing residential dementia care services** and their failure to consistently deliver high quality, person centred care.

- **Escalation from EMI Residential settings to EMI Nursing**. Individual's are frequently labelled as "challenging " rather than the service being seen as failing to understand their needs and responding appropriately. It is our contention that if the quality of care in EMI residential care homes improved less people would be admitted to EMI Nursing homes and significant funds could be freed up by BCU Health Board to invest earlier in support services earlier on the '*dementia road'* We estimate this could be as much as £33k per week (see section 2.2.1 Costings)

- **A lack of places for people with early onset dementia** while Flintshire has developed some community based support for younger people with dementia it does not have access to any specialist residential facilities.

- **Lack of skilled workforce** to deliver person centred dementia care and particularly availability of Registered Managers with the skill knowledge and leadership skills necessary to develop alternative and sustainable models of dementia care across North Wales.

- **Failure of existing data systems** to record unmet need and provide real time information about service needs and outcomes for people with dementia to inform future commissioning.

Community Based Health and Social Care Services

- **There are gaps in both Health and Social Services provision resulting in inappropriate hospital admissions**. Feedback from Care Home Managers, Families and our 'tracking the journey' exercise evidenced that more could have been done by Community Health Services to manage people's health needs in their own home or residential settings.

[7] DaffodilCymru

- **There are insufficient Community Psychiatric Nurses for Older people in Flintshire**. We have been informed that Flintshire is the second least resourced Local Authority in terms Community Psychiatric Nursing provision for Older People. Currently there are only 6.8 CPNs in the Older Persons Community Mental Health Team this resource has reduced over the last three years by 3 full time equivalent posts.

- **Lack of 'in reach support' into the EMI residential care sector**. Timely access to all community based health services such as Community Psychiatric Nurses, Social Workers, Out of hours G.P, physiotherapy and Occupational Therapy could prevent hospitalisations

A case study to illustrate the lack of 'in reach'.

A 99 year old lady, who was a long term resident in a Flintshire EMI residential home, had been falling frequently and attending A&E. One Friday morning she had another fall and was taken to A&E, who declined admission. The home felt they could no longer manage her needs. There was no suitable alternative placement. Attempts to involve colleagues in Health were unsuccessful and the lady was discharged back to the home the next day. Over the weekend the Home was unable to meet this lady's needs and the Out of Hours Social Work Team was contacted. Arrangements were made for additional 1:1 funding over the weekend to reduce the risks of harm. The lady continued to deteriorate and had to be admitted to hospital once more as an emergency on the Monday morning. Following assessment in hospital she was subsequently assessed as requiring Continuing Health Care and placed in an EMI Nursing Home out of county.

Carers

- **Carers and families of people living with dementia need to be better informed.** Carers told us they wanted better education specific to dementia, as well as timely access to useful information on what support is available to help them in their caring role.

- **Homes do not consistency work to fully involve families** and use them to learn about the person's past which is essential for developing 'life stories'. Homes could be doing more to involve families in the daily life of the individual within the home.

- **Carers need more help to understand what 'good' dementia care looks like.** This was evidenced by the inconsistency between judgement of performance through contract monitoring and the views expressed by older people and their families. We believe that carer's

expectations are limited to the belief that all a care home can provide is a service that delivers ‘bed and board’.

Finance

- **Access to capital funds for new provision in the current economic climate**. The private sector’s access to capital funds to develop new build projects or modernise existing facilities is limited and generally companies will only consider investment if a percentage of placements are underwritten by the Authority in order to mitigate risk. Most EMI residential provision in Flintshire is based on small business models owned/ managed by a single person as opposed to large corporate organisations. The majority of these facilities are old properties (some within listed buildings) where refurbishment or redevelopment would be problematic.

Section 6 - What we will do

6.1 Regional Collaboration

We will continue to work with colleagues from across North Wales in the Regional Commissioning Hub to develop an enhanced specification for the delivery of dementia care in long term settings. The Regional Commissioning Hub has been fortunate to secure short term funding over the next 3 years to develop consistent dementia services across the region that deliver person centre care. The Hub recognises the vital importance of developing a joint approach with the NHS and that collaborative working is the key to ensuring that we improve services for people with dementia across the whole of North Wales.

We are keen to share our learning from developing this strategy with the members of the Regional Hub. We hope that we can influence the debate about how the model of dementia care should look in the future. This strategy identifies key building blocks necessary to underpin the cultural change in attitude required if people with dementia in long term placements are to enjoy fulfilled and meaningful lives.

6.2 Flintshire's joint solution with BCU Health Board

We seek to engage commissioners within BCU Health Board to agree a shared vision of integrated community based services specifically to meet the needs of people with dementia and their families. We wish to explore the potential for securing better value for money through joined up service arrangements that support people early on the '*dementia road'* and as the illness progresses intervene actively to maintain individuals in current settings, preventing a crisis and escalation to inpatient beds or EMI Nursing provision.

6.3 Our vision for 'good' dementia care

We want to be proud of what we commission and work with all our EMI Residential and Nursing Home providers to develop consistent high quality person-centred dementia care in Flintshire. Through developing an enhanced specification for dementia services and recognising best practice in service delivery models such The Butterfly approach[8] we want to reach a shared understanding with all our providers and families on what 'good' dementia care should look like.

In Flintshire we are developing outcome based contracts with our Providers that are linked to clear quality indicators and outcome measures for those people living in our Homes. Flintshire's Contract Monitoring Team place greater emphasis on observing and evaluating those aspects of a service that impact most on the quality of daily life for residents in Care Homes, and seek to be able to measure the success of specialist dementia services in terms of the outcomes achieved for the individuals in that setting.

[8] Dementia Care Matters

We believe it is important to be open and transparent with our Providers describing clearly “good” practice and even provide examples of “exemplar” performance that Providers can aspire to. We have begun to pilot this approach and apply a “judgment framework” in recent Monitoring reports as we believe this approach will aid the development of a shared understanding of quality and best practice.

.

We believe the key elements are captured below:

1. A Home that has a manager who is a true leader in dementia care and leads a staff group who are skilled in person -centred planning and emotional intelligence.

2. A Home that adopts a model of dementia care that sees the person as an individual and treats them with dignity and respect.

3. A Home where the staff group know what is important to each individual they support and record this using person centred tools.

4. A Home that brings out the best in people that is pleasant, warm, and busy.

5. A Home where people's personal possessions are treasured and staff support people to take care of them.

6. A Home where everyone understands how to respond and communicate with the people who live there.

7. A Home where people are supported to make choices and decisions every day and 'best interest' meetings are used.

8. A Home that supports people to initiate and maintain friendships and relationships.

9. A Home that matches people with dementia together based on where they are on their dementia journey.

10. A Home that actively involves family and friends in the home and seeks to educate them about dementia.

11. A Home that undertakes quality assessments on admission and place great importance on using a person's 'Life Story' to plan their care and support.

12. A Home that ensures people's independence is maintained and promotes positive risk taking with the use of equipment and assistive technology.

13. A Home where there is meaningful occupation for everyone and individuals feel that they matter.

14. A Home that provide opportunities for people to go out and about and be part of their local community.

6.4 'A Road Less Rocky for Carers'

6.4.1 We will seek to develop a Carer's Course that is specific to the needs of carers of people with dementia. We will use the Carers Trust report [9] to guide its content and ensure that all relevant areas along the '*dementia road'* are addressed so that carers feel better equipped in their caring role. This will require working in partnership with Carers, Health, the Voluntary Sector and current providers of dementia services to agree and deliver a rolling programme of sessions. We will consider showcasing such courses within existing homes and hopefully in the future our first ***dementia café*** in Flintshire.

6.4.2 We will ensure that carers are treated as equals within the care management process. We will seek their contribution to develop accurate 'life stories' and profiles of the person with dementia. Assessments will focus on strengths and the positive contribution both carers and cared for can make in planning for the future. Care Management Assessors will be trained to identify clear outcomes for providers to build on within the residential setting.

6.4.3 We want to be a 'listening' organisation and establish an open dialogue with carers and other professionals who visit our EMI Care homes. We will introduce a range of mechanisms for people to be able to provide feedback both negative and positive on their experience of visiting our homes and what they observe. This will feed into our contract monitoring process and influence future commissioning decisions. Alongside this we are equipping our Contract Monitoring Officers with observational skills to measure the progress of providers in delivering 'good' dementia care. This will be based on outcomes achieved for individuals such as improved physical health, visible signs of emotional well being and the level of positive engagement between staff and individuals within the home.

6.5 Skill up the Workforce

Flintshire provide training vouchers to support all providers comply with regulatory training requirements. We have made a significant investment in commissioning a range of specialist training for providers supporting people with dementia, this includes "All about Dementia",to offer training opportunities to our 8 independent sector care homes. The training will help care staff to improve how they communicate and engage with residents who have Dementia. There is also a specific course for Home Managers of specialist Dementia Home's that focuses on the leadership skills required to bring about cultural change and real person centred care practices. In addition a programme for " Assessors" is currently being rolled out to our Social Work Teams. This will enable our staff to examine the strengths and weaknesses of the current Unified Assessment tool and seek to build a better understanding of the importance of 'life stories' and relationships in care planning. We believe we have made a positive start on skilling the workforce but recognise

[9] A Road Less Rocky – Supporting Carers of people with dementia 2012

that Training alone is not a solution to ensuring quality and that we have some way to go.

Section 7 - What Next?

We will be producing a Market Position Statement based on this strategy which will clearly state what we want from dementia care long term placements. This will be our 'calling card' to Providers, including a clear signal to established Social Enterprises to work with us.

In the short term we will continue to have an open dialogue with our Providers about how to meet the shortfall in EMI Nursing Home places within Flintshire boundaries. This will include supporting those providers who are interested in re-modelling their current service to provide EMI Nursing places in the future. We will continue to provide advice on person centred tools and approaches and encourage the sharing of best practice across all EMI Nursing and Residential Homes. Our aspiration is to support one Flintshire home to adopt the "Butterfly" approach and be established as a demonstration site working to achieve the butterfly kite mark in Dementia within the next 3 years.

In the longer term we will consider developing more Extra Care facilities with designated apartments for people with dementia within Flintshire in order to extend the range of options available as an alternative to traditional long stay care. We will continue to work closely with the Regional Hub to commission specialist services for people with early onset dementia and those with other complex conditions in need of a long stay placement.

We will strive to maintain the positive working relationships that exist at an operational level between Social Services, Community Psychiatric Services and Community Nurses within Flintshire localities. We will seek to build on this at a strategic level through ongoing dialogue about realigning or pooling funds and an integrated approach to prioritising available resources in Health and Social Services.

We believe that the planned integration of our Social work Teams and some Community Health Care Services within three "Locality Teams" across Flintshire will drive forward a more joined up approach, enabling more efficient and responsive services to develop on the ground. The Flintshire strategic Locality Board was established in 2010 as the mechanism to oversee and steer this work and resolve organisational or system issues that may challenge practitioners and prevent the delivery of coordinated and timely intervention. The "South " Locality Group has been identified to lead on the development of services for people living with Dementia .

Section 8 - Conclusion

Our Council like others is facing unprecedented financial challenges and raising expectations as such we have to do 'better with less'. Our ultimate goal is therefore to provide and commission the best possible services with the money we have available.

This Strategy has provided a strong rationale based on the best information we have that we need to act and do things differently. This is clearly " work in progress " and while there are some things that are within our control and we know can be improved in the short term there are others which will require more sustained and longer term Regional Collaboration to effect change.

Our Modernising Social Services Board and Annual Council Reporting Framework will be the mechanisms for monitoring the progress of this important strategy.

Acknowledgements

We would like to thank all the following people and groups who influenced this strategy especially people with dementia and their families who took the time to complete surveys and take part in discussions.

Cilcain Women's Institute
Mold Rotary Club
Flintshire Advocacy Services
Douglas Place Luncheon Club, Saltney
Dignity Champions Network
Councillor Christine Jones, Older People's Champion
50+ Action Group
NEWCIS (North East Wales Carers Information Service)
Care Checker – Laraine Bruce and Roger Rowett
EMI Care Home Managers
Locality Teams (Social Workers and Occupational Therapists)
Flintshire Contract Monitoring Team
Flintshire Local Voluntary Council
Flintshire Tenants Liaison Officer
Early Onset Social Worker
Members of the Older People Commissioning Board
And everyone who helped distribute the surveys

Front cover images by courtesy of www.careimages.com

Section 9 - Appendix

Appendix 9a - Costings

Residential & Nursing

Cost from FA up to date 31/03/13 and any know changes thereafter up to 10/06/2013

Gross cost less PAA

	Flintshire		Out of County		Part 3	
	Weekly Cost	Annual Cost	Weekly Cost	Annual Cost	Weekly Cost	Annual Cost
Number of Clients	**100**		**28**		**7**	
EMI Residential	£49,322	£2,564,744	£13,749	£714,954	£3,373	£175,415
Less personal applicable amount	-£12,092	-£628,784	-£3,386	-£176,060	-£846.44	-£44,015
Total	**£37,230**	**£1,935,960**	**£10,363**	**£538,894**	**£2,527**	**£131,400**
Number of Clients	**8**		**31**			
	Weekly Cost less Free Nursing	Annual Cost	Weekly Cost less Free Nursing	Annual Cost		
EMI Nursing	£4,238	£220,351	£15,995	£831,746		
Less personal applicable amount	-£967	-£50,303	-£3,749	-£194,923		
Total	**£3,270**	**£170,048**	**£12,247**	**£636,823**		

% Split

EMI Residential	74%	21%	5%
EMI Nursing	21%	79%	

Appendix 9b – The Views of Stakeholders

We received an enormous amount of feed back in the course of developing this Strategy from a wide range of stakeholders; each section that follows is underpinned by a detailed feed back report which is available on request.

For the scope of this strategy we have extracted the 'key messages for commissioners'. We have also shared relevant views/ feedback on health service provision with our Health Partner.

1. Older People with Dementia and their Families

1.1. The keys themes for our strategy from National consultation is as follows:

In the declaration for England cited in Dementia 2013, developed by the Dementia Action Alliance (DAA), people with Dementia and their carers describe seven outcomes that are most important to their quality of life, which echo themes coming from other research –

- I have personal choice and control or influence over decisions about me.
- I know that services are designed around me and my needs
- I have support that helps me live my life
- I have the knowledge and know-how to get what I need
- I live in an enabling and supportive environment where I feel valued and understood
- I have a sense of belonging and of being a valued part of family, community and civic life
- I know there is research going on which delivers a better life for now and hope for the future

More than 70% of the UK public said they would feel scared about moving into a care home in the future. However, in the same report by Alzheimer's Society 2013 it was found that 74% of carers would recommend the care home the person with dementia was in, but note less than half (41%) thought that the quality of life of the person with dementia living in the care home was good. This suggests more work is needed to promote and improve quality of life of people with dementia in care homes.
The findings also seem to indicate that we also need to work with families and carers to raise their expectations.

1.2 Three Listening events were held in each of the three Localities of Flintshire.

1.2.1 Listening Event **-** Consultation with the Women's Institute, Cilcain
9th September 2013. 20 members attended.

Key messages for Commissioners:

- Care Homes should have more activities to provide stimulation, e.g. music sessions, reading groups.

- Focus on family stories: knowing the person and their family life is important; photographs and personal items can be used to aid memory.

1.2.3 Mold Rotary Club, 30th September 2013. 20 members of the Mold Rotary Club attended (all older gentlemen).

Key messages for commissioners:

- Ensure early identification and diagnosis
- More memory specialists (suggestion G.P's could offer routine screening)
- The quality of information and advice is important
- Carers need to be directed to appropriate support.
- More support for people with memory problems.
- People need to know what support is available.
- Focus should be on providing good care in the person's own home
- Opportunities for people to engage in stimulating activities based around memory training. Activities that are community based, maybe a 'club' environment and encourage links with young people.
- Knowledge and understanding of the person is very important, clear communication is essential as is opportunities for one to one interactions. Communication in the preferred language is important.
- Ensure home environments are welcoming and that people with dementia feel safe.

1.2.4 Douglas Place Luncheon Club, Saltney, 6th September 2013. 20 older people attended (18 women and 2 male volunteers).

Key messages for commissioners:

- There is not enough support available for people with memory loss
- There is not enough information about memory services and support
- More respite and education opportunities for carers.
- The importance of friendships for people with dementia
- Close knit communities are needed, the Community Support officer role is important at Douglas place.
- Encourage young people to help more in their communities.
- People with memory problems need places that are welcoming and where they can meet other people and have someone to talk to. Choosing the right place to meet is important, and it should a place that is known to the community.
- Group activities that are entertaining and interesting/ keep people with memory problems connected. e.g. someone to accompany them to go shopping or support to remain familiar with the community.
- Wardens in supported housing have a large network of contacts with older people and they could be a good source of information and advice for people with memory problems.
- Memory services need to be local as the cost of transport can be prohibitive.

- People must be treated as part of the community and with dignity and respect, and be included in the life of the community.

SUGGESTED IMPROVEMENTS list:

- better transport
- more music groups
- lunch clubs with volunteers who understand memory issues
- more information about memory issues
- more respite services to help carers
- local memory activities and more activities for men
- trained volunteers who are 'memory support friends' in the community
- better access to basic services e.g. chiropody, help with gardening / handyman

1.3 Consultation with the **50+ Action Group**, at the Older People's Association, Connah's Quay, 9th September 2013. 11 members attended.

Key messages for Commissioners:

- Ensure that the plan is workable in practice
- Ensure the involvement of the Health Board in the plan and in the implementation of the plan
- Secure the involvement of mental health nurses with expertise in dementia
- Provide the training that staff require to support the plan
- Consult with other local authorities in England and Wales to identify best practice, but if possible visit these 'best practice' sites to see services in action.

1.4. Survey to obtain the views on choice, care and community for people with dementia in Flintshire care homes.

The survey and resultant write up is closely based on the research undertaken by the Alzheimer's Society which was published in 2013.

In Flintshire we distributed the survey via care homes, Social Services, voluntary sector partners and direct to Social Services staff. In total **32** surveys were returned[10]. Even though our numbers are small the findings and conclusions are in the main in line with the national research undertaken by the Alzheimer's Society.

The keys messages for the Commissioning Strategy are as followed:

- Feedback on current provision was mainly positive, good value for money and many would recommend.
- Ensure that there are opportunities for residents to get involved in activities, to socialise, with trips out.
- Involve volunteers and local schools

[10] Note 4 surveys were returned after the deadline and therefore not included in the data analysis, however all four were screened for themes and comments.

1.5 Survey to obtain the views of family/ carers of people with dementia, who live in the community on what things, would be important if they had to choose a care home

The survey and resultant write up is based on the research undertaken by the Alzheimer's Society which was published in 2013 and David Sheard's Inspiring Checklist.

In Flintshire we distributed the survey via care homes, Social Services, voluntary sector partners and direct to Social Services staff. In total **26** surveys were returned[11]

The keys messages for the Commissioning Strategy are as followed:

- Ensure staff are trained in providing dementia care.
- Ensure homes are clean
- Ensure homes are appropriately designed with the right layout for people with dementia
- Ensure residents remain active

1.6 NEWCIS Carers Event 28th Sept 2013. 17 carers attended.

Three questions posed**:**

1) 'What could have been an alternative to long-term residential care for your relative?' and 'How would you have designed this?'

The key messages for commissioners are as follows:

Communication & Information

- Better communication between Social Workers and G.Ps
- More information on available support in G.P practices and clinics.
- Carers should always be treated as equal partners in the delivery of care.
- Provide timely information so that carers can make informed decisions e.g. about long term care etc.
- Carers to have one named person as the point of contact, to avoid having to deal with different professionals.
- Ensure all Social Workers are informed about what dementia services are available.
- A prompter and more proactive response in offering support such as respite.
- Consider holding meetings away from Social Services where carers can meet with the professionals from different agencies.

Support Services

- The need for male carers
- More support for carers in their caring role and help to lead a life outside of caring.

[11] Note 4 surveys were returned after the deadline and therefore not included in the data analysis, however all four were screened for themes and comments.

- The need for age appropriate services for people with early onset dementia
- Greater creativity and more options with respite e.g. respite in familiar surroundings such as the person's own home
- The importance of having consistency in paid carers supporting people with dementia and less rigid times for visits
- More Living Well provision

Image & Practice

- Reduce the 'red tape' to make it for carers to understand and navigate the system.
- Address the poor public image of social services which serves as a barrier to engaging carers.

Q2. How important is the physical environment in your choice of care home?

The key messages for commissioners are as follows:

Selecting a Home

- Signpost carers and people with dementia to Inspection

Approach of the Home

- An open visiting policy
- People can stay at the home when illness progresses and Category changes.
- Inclusive of family and friends e.g. first name terms, host wedding anniversaries etc

Physical attributes that are important:

- Internal space that is safe for people to wander around
- The home is odour free
- Gardens and outdoor space e.g. 'I like to walk the dog with my grandad'

Q3. What kind of support makes the most difference to your relatives general health and well-being?

The key messages for commissioners, as follows:

- Respect individual choices
- Homes that support people to maintaining contacts within the community.
- Homes that support people to maintain interests, not just Bingo or sing-a-long.
- The importance of continuity of care, same carers, same respite facility.

1.7 Care Checker in three in- house homes, 16 family members took part. The information gleamed was extremely in depth and rich and would suggest that the full report is requested.

The keys messages for the Commissioning Strategy are as followed:

- Focus groups for families during which they could share learning, good practice and at the same time support one another.
- Are older people's expectations limited by the lack of expectations and aspirations that family members have? For example, a belief that all that can be provided is (hopefully) a quality service based on bed and board!!
- Idea of relatives as informal trainers for staff. Also regular relative meetings.
- Relook at the role of the social worker in this process. Also, communicate to all involved parties "who is responsible for what?"
- Explore further the advantages and disadvantages of dementia units within care homes.
- Continuity of support is central and identified as the most important factor in the provision of a quality service. This centred around the importance of knowing the individual and also the family.
- The idea and practicalities of a 'transitional' team of people involved in the life of each person could be considered. It could commence at the point of referral and continue through all stages of the service provided. It could also involve staff from the commissioning team, care management, provider and links with other agencies. Importantly it would have the person at the centre, together with involved family and friends. A bespoke team for each individual - a dedicated circle of support. This would carry varied levels of involvement and responsibility, but if 'chaired' by a key person in order that information is coordinated and communicated well, then the benefits for all stakeholders could be immense.
- Utilise the interests and skills of relatives wherever possible. The idea of a relatives support group was considered. This could encompass a variety of things e.g. welcoming new relatives, sharing experiences, looking at ways of improving the service, safeguarding, provision of training for staff. The last could be really helpful prior to and in the early stages of their relative's admission.
- Challenge is to create services/supports that are flexible and responsive to the changing stages of each person's dementia. Recognised that this can only be achieved via a mix of formal and informal support.

2. Current EMI home care providers

A 'Strengths, Limitations, Opportunities and Threats' Tool (SLOT) was used to structure 1:1 interviews with a random selection of 8 EMI Home Care providers.

The keys messages for the Commissioning Strategy are as followed:

Families

- People and their families appreciate good planning and timely moves into Care Homes
- Families want easy access to information and professionals, with good signposting to support.
- It is important to actively involve families in the running of the home via family groups.
- The need to educate families on the importance of 'life books'

Health Services

- The need for there to be better communication between Homes and Hospitals.
- It is vital that all ward staff understand dementia and work to help people maintain their independent skills.
- People with dementia should always be treated with dignity and respect.
- The importance of smooth and effective discharge practices.
- Timely access to community based health services such as Community Psychiatric Nurses, Out of hours G.P, physiotherapy and Occupational Therapy could prevent hospitalisations

Categories

- There is the need for clarity on the criteria that qualifies someone for EMI nursing as opposed to EMI residential. Home Managers reported that people with very complex needs are now being classed as EMI residential.
- Getting the placement right is vital for the person, other residents and staff.
- The use of variations by homes can lead to stress and anxiety for other residents as people with dementia have specialist needs.

Training

- Invest in training, target health professionals and hospital staff and tailor for home care staff.
- Invest in leadership training.
- Those arranging training should acknowledge the need for managers to work rotas, always ensure prompt notification and confirmation of place.

Best practice / person - centre care

- Homes want to embrace best practice and person centred care, examples of approaches and tools currently in use include My Home Life -person centred care and relationship centred care, 'challenging

snake', key worker group model, active support model, life books, reflective practice, seeking design advice for new-builds, use of technology
- Create opportunities for Home Managers to meet and share good practice

Financial viability
- Fees currently do not reflect the complexity of need and what commissioners expect
- The value of volunteers to help deliver person-centred care and provide 'quality' time activities
- Homes need to be bigger to be financially viable
- Concern about the vacancies that exist in EMI residential homes
- The changes in employment e.g. the auto enrolment into pensions could potentially increase staffing costs by 3-5%, profit levels falling year on year

Social Services
- The link to Social Workers is important.
- Care plans need to be promptly completed once decision to move into a home has been made, and need to be detailed especially in relation to challenging behaviour.
- Families would welcome a quicker financial assessment process.
- Self funders should be supported/ safeguarded in the same way as Local Authority residents.

Commissioning & Regulators
- Policies are difficult to see through to fruition without adequate funding
- Local Authority commissioning intentions to be published so homes can financially plan
- Flintshire County Council as a provider and commissioner is a conflict of interest as will always fill own homes first.
- Recognition of the willingness amongst commissioners to work and engage with sector to develop betters models of care
- Address inconsistencies across homes in terms of standards/ messages from inspectors
- The need for more robust monitoring of whether staff in homes are trained
- Suggest that failing providers are suspended from the approved provider list (APL) which is shared with families looking for potential homes.

3. Locality Teams (Social Workers and Occupational Therapists)
A 'Strengths, Limitations, Opportunities and Threats' Tool (SLOT) by the team
The keys messages for the Commissioning Strategy are as followed:

Strengths [prompts: what currently works well, think outcomes, cost effective etc] Dementia Support Workers Premier support (55hrs) Dedicated Social Worker Living Well service 1 – 2 – 1 crisis intervention (fast response) Specialist Day Care (inc Alzheimer's) Telecare extra care, people can remain with life partners	**Weaknesses** [prompts: gaps in provision, unmet needs etc] Lack of co location of services for dementia Joint closer working with Health No specialist respite care for Younger Onset Dementia Care at night EMI Nursing Beds people out of county - block beds Caring for carers Quality of meals being offered within 30 minutes
Opportunities [prompts: ideas/models for best practice, what works well elsewhere, potential innovation] Dementia Café Llys Jasmine Dementia Action Plan (focus South Locality) Specialist OT post (dementia) hands on Enhanced Care create an enhanced service (with GPs) – when people move into a home Look at telecare Social enterprise Look at contracts with care home providers to look at dining room environment	**Threats** [prompts: processes, relationships, finance, risks etc] Demographic increase in population Rising expectations on Residential Care Homes (families wanting Residential Care) "EMI" use of language & labels Lack of joined up Commissioning Plan EMI Respite Care beds based in ordinary Residential Care settings Fear of payments Perception – people feel they will be put in homes Huge effort of engaging with patients (with dementia) Lack of information

4. Commissioners and the Contract Monitoring Team

A 'Strengths, Limitations, Opportunities and Threats' Tool (SLOT) by the team
The keys messages for the Commissioning Strategy are as followed:

STRENGTHS	**LIMITATION**
• Specific day centres i.e. old brewery, Croes Atti • Quality monitoring • Strong working relationship i.e. health professionals, independent sector • Training in partnership with independent providers • Choice across the county (EMI Residential) • Knowledge and intelligence of the market • Open market facilitation, working well together, informal discussions • Extra Care project in – Llys Jasmine • Pockets of good practice in some residential settings involving change culture and practice • Flintshire has good strong links with other agencies i.e Alzheimer's society and the Regional Dementia task group involving the independent sector and other stakeholders • Strong relationships and engagement with the independent sector and contract monitoring and commissioning	• Large variance of dementia knowledge of some managers in the market • Lack of resources to enable people to access their community and links when placed in a residential home and over 65yrs • Lack of understanding from the assessor at initial assessment – care planning is often not outcome focused or person centred • Historic culture and expectations • Everybody has a responsibility to deliver meaningful activities i.e. environmental and therapeutic – i.e. handyman, carer to domestic care, this is everyone's responsibility • Lack of EMI nursing • Social Services and Health colleagues are currently doing very little joined up working, duplication of process taking place adding additional pressure to providers and families i.e. reviews • Lack of safe out door space in some residential homes
OPPORTUNITIES	**THREAT**
• Regional Monitoring framework • Work with existing practitioners and residential setting to change the culture • Opportunities to develop and maintain meaningful daily activities • Work with the independent sector to develop family forums to assist with education and training of dementia to assist to maintain a meaningful relationship with their relative • Dementia training for the contract monitoring and commissioning team • Model of care – home for life rather than having to move on when enhanced care is required	• CSSIW removal of categories • Home in administration • Escalating concerns • Lack of EMI Nursing care • Voids in EMI Residential • Current economics environment i.e. strategic funding • Higher level of dependency at the point of accessing services • Model of care – home for life rather than having to move on when enhanced care is required • Statistics show a high turn over of Registered Managers • Employment Terms & Conditions do not reflect specialist skills and additional training required to deliver dementia care

5. **Dignity Champions Network** Workshop for the Flintshire and Wrexham Dignity Champions Network**,** 2nd September 2013. Attended by 17 members of the Flintshire and Wrexham Dignity Champions Network, including representatives from the Local Health Board, the Community Health Council, Flintshire County Council, Care Homes and Nursing Homes, British Red Cross, Neurological Alliance Wrexham, Parkinsons UK, and the Cymru Older People's Alliance.

Q. How can we support dignity in care for an older person with memory loss living in a long term placement? What works well and what could we be doing better?

For people with memory loss living in long term placements, dignity in care can be supported by achieving early diagnosis and good follow up and communication across professional groups.

Care plans must be person-centred and reviewed regularly. Details of the care plan should be communicated to the person with dementia and to carers.

Staff can create a helpful environment, focusing on structure, continuity, consistency, respect, person-centred care, and privacy. Helpful reminder notices can be used throughout the environment, creating an atmosphere of comfort and safety.

The atmosphere should be inclusive for all residents. The person should be listened to in a respectful manner and their wishes and choices respected. Staff should approach the person with empathy and understanding.

The 'life story' approach works well provided staff are trained to apply it in their daily work. Care staff can use family photographs, films and objects from the person's era, to create an understanding of the whole person.

Respect for personal appearance and for personal items is important; keeping personal things close to hand and not moving them without consent. Enabling people to have a single room and their own bedding enhances dignity in a residential setting.

Providing opportunities to engage in activities through volunteer support, focusing on memory activities and reminiscence, chatting and themed sessions, and making more activities available than is currently the case.

How the care in long term placements could be improved :

- Allowing more time for staff to spend on reminiscence work
- Mandatory training for all staff in dementia care
- More training for staff to translate 'life story work' into daily practice
- Providing care in the person's preferred language
- More opportunities to share expertise between staff, expert individuals and groups (e.g. universities working with staff in care homes)
- Regular audits of quality in dementia care; and a re-assessment of how we measure 'quality' in dementia care
- More consideration given to staffing levels and the availability of care at home
- Increase awareness of the NICE guidelines on dementia care

6. Response from Councillor Christine Jones, Older People's Champion, Flintshire County Council (10th October 2013)

Services should be focusing on providing support for people to live a normal everyday life in their own home for as long as possible. It is important to provide care at home for as long as is practicable, and relatives need support from health professionals, social services and the voluntary sector.

Care at home should be fully supported to avoid admissions to hospital. Admission into hospital for care can cause confusion due to the sudden change of surroundings. When discharged from hospital, whenever possible older people with memory problems should be able to return to their own home with support. Discharge into a care home should only be considered as a secondary alternative to discharge to their own home.

We need the full support of GPs to provide good quality services, and we need to make sure that high quality training in dementia care and dementia awareness is available to GPs, all community health care staff, carers and families. Relatives and carers need support, information and training to cope with this complex condition, and the availability of good respite care is also essential.

We need more Extra Care housing schemes for people with dementia, and the Llys Jasmine development is a very good example. Having apartments specially designed for people with dementia, while also having integrated facilities where all the residents can come together is an excellent model.

David Sheard's ideas and practices around dementia care should be given full consideration.

7. Flintshire Advocacy Services.
Key messages from Advocates:
Address waiting times for OT and Occupational health,
There is a lack of EMI nursing home placements in Flintshire
Some homes need more staffing at night.
More staff training and knowledge on specific illnesses
There is a lack of facilities for younger dementia sufferers
Access to facilities when in residential care e.g. day centre/ day care in particular for younger dementia/brain acquired injury.
Knowledge of Mental capacity Act and in particular DOLS probably in all areas

Appendix 9c - Tracking Nursing Home vacancies