The Needs of Informal Carers of Those Living with Dementia

Author: Sally-Ann Spencer Grey - Independent Lecturer and Consultant
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Hull Churches Home form Hospital, Carers’ Support Scheme
1st Floor, 82 Princes Avenue, Hull, HU5 3QJ
Email: carerssupport@hchfh.org.uk
Tel: 01482 475265

Author contact details:
Email: sally@saspencergrey.co.uk
Tel: 0845 686 0211

To reference this document:
Executive Summary

Introduction
Hull Churches Home from Hospital Services (HCHfH) is an independent, registered charity in Hull, established in 1993. It provides a range of high quality short-term support services to the people of Hull that include:

- Vulnerable older adults – The Adult Service
- Informal carers – The Carers’ Support Scheme
- Children and families – Families Together
- Telecare/TeleHealth

The charity successfully secured a grant from the Department of Health’s “Reaching out to carers innovation fund 2010/2011” to support this needs analysis of the needs of informal carers of those living with dementia.

Dementia
‘Dementia’ is an umbrella term used to describe the symptoms that arise because of loss of brain function from a range of diseases or conditions. Late onset dementia (over age 65) is considered a common condition associated to older age (though not an inevitable consequence of ageing) and is slightly more common in women than men. Though less common, ‘early onset’ dementia (under age 65) is also evident.

Dementia is life-shortening but life expectancy is unpredictable; the median life expectancy is about 8 years from onset of disease. Dementia is associated with complex needs and high levels of dependency and morbidity which has a huge impact on individuals and their families but also on health and social care resources.

Dementia Demographics
Approximately 2,630 people in Hull have some form of dementia today; of these just 900 currently have a registered dementia diagnosis. A third of people with dementia live alone; in Hull this could be over 870 individuals. In Hull in 2008 it was estimated that 919 individuals with late onset dementia were living in some form of care home. The number of people in Hull living with dementia is likely to rise by roughly 30% by 2025.

50% of all cases of dementia have a vascular component; atherosclerosis is a risk factor for vascular dementia and risk factors for atherosclerosis are associated to deprivation. Deprivation is also associated to higher incidence of dementia in younger age groups (age 60-79 years). Hull City Council is the 11th most deprived local authority (out of 354) in England, and is in the bottom 10 - 20% deprived nationally in most domains.

The Carers
People with dementia are often old and frail and family carers, commonly a spouse, are also old and frail themselves. Some do not really see themselves as ‘carers’ and most consider their caring role as a natural consequence of their relationship with the person with dementia. Many carers continue to see themselves as carers even when the person with dementia has moved into a care home.

The experience of living with dementia is highly distressing and difficult. Even with good support carers often find it difficult to know how best to respond and there is potential for conflicts of interest between the person being cared for and their carer(s) and family.
Informal carers are entitled to an assessment of their needs in order to access help and support services; a half to two-thirds of all carers do not receive a carer’s assessment. None of the carers interviewed reported having had an assessment.

Research suggests that couples, especially older couples, should be evaluated as a unit and any interventions developed should focus on the needs of both individuals simultaneously.

It is suggested that the frequency of day-to-day problems (psychiatric symptoms and behavioural issues), and not the degree of cognitive impairment or difficulties with activities of daily living, are the dominant causes of carers’ stress. Caregiving burden is associated to carers’ stress, psychological distress and poor physical and mental health of carers and can reduce their life expectancy.

The ‘tipping point’ for care home placement is the point where the carer can no longer physically or emotionally cope with providing safe 24 hour care that the person with dementia needs. Issues contributing to this ‘tipping point’ include:

- Stress
- Sleep deprivation
- Increased frequency of day to day problems and crises
- Challenging behaviour
- Lack of practical and emotional support
- Social isolation
- Stigma and shame
- Physically can no longer manage e.g. moving and handling
- Financial cost
- No longer able to ensure the safety of the person with dementia in that home environment e.g. wandering, falls or abuse
- Incontinence in the person with dementia
- Mental illness in carer e.g. depression
- Physical illness in carer
- Physical illness or injury in person with dementia e.g. hip fracture

**Early Diagnosis**

Whilst the benefits of early diagnosis and intervention in dementia are well documented and are policy directives nationally and locally, this is not always easily achieved; making a diagnosis of dementia is often difficult and there is poor detection and recognition of dementia by GPs. Poor recognition of memory problems by carers and the person with memory problems can also lead to late presentation.

**Models of Care**

Modern dementia policy and research advocate a shift from a medical approach to dementia care to enable innovative psychosocial and re-enablement models of care to be adopted. This new paradigm consists of person-centred holistic approaches, with application of a social model of disability and positive risk management, whereby the person with dementia and their carer are both active partners in the care process. This can lead to redefining dementia as a manageable disability.

Whilst policy adopts this paradigm, current service provision lags behind. Dementia services in Hull are typical of dementia services found in much of the UK. They cut across mental health and older people services alongside primary care, social care, acute care, care homes, and the independent, charity and voluntary sectors. Funding sources vary, there is no overarching
coordination of services, and advance care planning and end of life care planning are both under-developed in dementia care.

This is a period of significant change in health and social care generally and whilst it may be a difficult period it also presents some great opportunities for innovation and will provide some particular opportunities for the voluntary sector.

**Workforce and Dementia Services**
Nationally the current health and social care workforce is considered too small and is generally ill equipped to provide high quality dementia care. Training alone will not address this; organisations must also value good care (APPG on Dementia 2009).

Whilst current local services are insufficient to address the existing issues there are pockets of innovative developments such as the Hull Memory Clinic and their stepped approach to care, and a local dementia strategy has been implemented which has led to some service development, new roles and services; further developments and new services are planned.

**Services for Carers**
A key message regarding services provided for carers is that one size does not fit all – services must be varied and flexible, in order to be able to respond rapidly to changes to carer’s needs.

Carers want active help and support that will stimulate the lives of the person they are caring for as well as providing stimulation in their own lives. Having the opportunity to address the changes in sexual intimacy in their relationship is also important to many couples.

Resources made available for carers should be available round the clock, every day and should include:

- Assessment
- Information
- Early support and counselling
- Education and training
- Therapeutic interventions for challenging behaviour
- Carer support groups
- Advocacy services
- Short break/respite care
- Day care and day opportunities
- Home support services
- Environmental approaches and crisis intervention services

The aim of interventions and resources for carers for people with dementia have been defined as enabling carers to continue caring for the person with dementia in their own home for as long as practical; enabling carers to maintain a caring relationship between them and the person with dementia; and enabling carers to feel fulfilled and satisfied in their caring role.

Carers are often unaware of what care and support may be needed, or is available, or how it can be accessed (‘How the system works’). Carers may not seek help as early as they might as it takes time to realise they are not coping and they may see seeking help as an admission of failure. Social isolation and living in a deprived community are also associated to lower rates of service utilization and higher rates of refusal of services.

Activities and services that can impact upon carers’ social isolation in particular include:
• Volunteer befrienders  
• Peer support and groups  
• Counselling, including relationship counselling  
• Education and courses about leisure activities, stress management, dementia, communicating with someone with dementia and managing challenging behaviour.  
• The opportunity to tell their own story and reminisce.

Local Carers  
For this project 9 carers were interviewed. Whilst the limitations of this small number of interviews is recognised, the findings do provide a useful snapshot of caring for those living with dementia in Hull and also correlate very well with themes identified in the current literature.

Carers discussed their fear of this disease and how the prospect and subsequent reality of a dementia diagnosis was devastating; they recognised the significant impact it would have upon their everyday lives and their hopes for the future. They also said that they were not always fully aware of the nature, causes, risk factors or likely progression of the dementia.

Carers could usually pinpoint a specific time when significant and noticeable changes occurred that necessitated medical assessment or intervention; it was only with hindsight that they could see that there was evidence of the disease being present much earlier. The changes identified varied and were usually quite subtle at first; some had thought these were just part of the normal ageing process, and consequently there was no thought given at all to assessment or diagnosis.

Some carers were very distressed, even years afterwards, that their lack of awareness of dementia had contributed to late presentation and missing the opportunity for early diagnosis and because they had treated this individual’s memory lapses as wilful or annoying.

Carers acknowledged that it could be hard to accept the diagnosis, once provided. They also reported that receiving a diagnosis did not automatically lead to access to appropriate services.

Many carers see their caring role as part of their personal commitment to that individual and a natural expectation of their relationship with that person. Most carers, particularly spouses, see residential care placement for the person with dementia as a last resort and only to be instigated when the caring situation in their own home becomes impossible, usually meaning physically impossible. Carers stated that they found it difficult to identify when they are no longer coping and needed to be prompted to consider this. Some associated residential care placement with their failure as a carer. Spouses particularly do not seem to give much thought as to when or how such a situation might arise, and rarely have contingency plans in place in case of crisis.

Carers said they avoid thinking of residential care and end of life care because of:  
• Fears around the person being ‘taken away’ from them – of losing control over their care  
• Feelings around it being their duty/responsibility and they would feel they were breaking their wedding vows – “they are your responsibility”  
• Fear of losing the relationship - they have been married and living together for 50 or 60 years and probably don’t have much time left but what is left, regardless of quality, they want together.  
• Fear of loneliness
Fear of having to cope with the loss (grief and loss - pre bereavement) – having to acknowledge end of life issues – the hope that the person will come back to them even briefly (though they know this is unrealistic) lingers.

Carers often have feelings of guilt after care home placement, which persist even when carers truly believe it is the best thing and in their loved one’s best interests and they acknowledge they have better quality time with their loved one now. The carers interviewed did still consider themselves carers even if the person they were caring for was now in residential care, and most spouses visited every day for many hours.

**Recommendations**

**Local developments**

- “Investment is needed in local public health campaigns to reduce people’s risk of developing dementia in later life” (YHIP 2010 p9). This may also be an opportunity to involve carers in developing and delivering local health promotion activities.
- Develop advance care and end of life care planning processes and implement these early whilst the individual with dementia maintains some capacity.
- Carers suggest that poor communication and record keeping could be prevented through the use of carer (home) held notes that they could contribute to.
- Make it easier for carers to find out what services are available and how to access them. This could be a carer led initiative.
- Key workers/family advocates could provide timely support to facilitate decision making and informed choice and signpost to other services. This support could be provided by a range of organisations - especially voluntary organisations such as HCHfH.
- More memory services will be needed to facilitate early diagnosis and timely support for the person with dementia and their carer.
- Involve carers and ex-carers in training and education for ‘new’ carers and professionals (staff and volunteers).
- Educate and support GPs, primary care teams and staff in acute hospitals regarding dementia and services available locally.
- Be aware of the impact that traumatic events, e.g. Flooding, can have upon the care of those with dementia.

**Recommendations for HCHfH**

The way forward for HCHfH is to build upon what they already do so well. HCHfH has an excellent track record for vision and innovation and articulates very clearly its current provider role with regards to personalisation - but also recognises its role as an educator and advocate for users and its role in positively influencing service development and delivery.

HCHfH also perhaps has a particular role to play in developing and supporting expert carers’ initiatives, advance care and end of life care planning processes and in supporting telecare/telehealth initiatives.

HCHfH is recognised for its short term support and volunteer befriending roles and its ability to be flexible and respond quickly to a crisis. The impact volunteers can have on social isolation, especially through providing support in a person’s own home, is well recognised. However, because of the nature of dementia HCHfH would need to develop longer term befriending relationships with carers looking after someone with dementia and the person they were caring for - perhaps identifying these as key worker or family advocate roles. Capacity to deliver
periods of more intense support at times and the ability to respond to crises would also need to be developed as part of these services and befriending roles.

Access to these HCHfH carers’ support services should not just be related to a formal diagnosis of dementia and should be initiated when memory problems are necessitating some informal care. The befriending role, together with information and support, may help carers and the person with dementia come to terms with what is happening in their lives and may help facilitate presentation for assessment and diagnosis. The support from HCHfH would need to continue through times of transition, which may require some intense support. Support provided to carers after residential care placement of the person with dementia would be orientated to helping carers to adjust.

HCHfH would also be an excellent partner in collaboration with other services, e.g. The Alderson Resource Centre, to develop active outreach and crisis intervention services.

HCHfH is also an excellent resource for advice and support and facilitative signposting to other services and would have a clear role in health promotion activities.

HCHfH will need to clearly identify the services it can support and sustain that complement existing provision, leading to the development of an appropriate strategy to address these in a timely and measured way. The following list of services and activities should be considered:

- Developing a dementia care education pathway for staff and volunteers
- Providing an ad hoc respite/sitting service
- Providing regular/scheduled short term respite/sitting service - e.g. time limited intervention, 6-8 weeks
- Providing regular less intensive but longer term support
- Providing practical help and support
- Providing crisis support
- Supporting quality time between the person with dementia and carer
- Providing support specifically to the carers
- Supporting carer involvement in service development and education
- Developing appropriate routes for referral/signposting to other agencies and services and helping to improve communication between services
- Advocating on behalf of carers and people with dementia
- Contributing to raising awareness of dementia
- Supporting psychosocial activities (e.g. reminiscence work)
- Promoting and facilitating advance care, crisis and end of life care planning
- Providing education and support regarding the use of assistive technologies
- Supporting carers and their families through the decision making process regarding care home placement
- Continuing carer support after care home placement
- Support carer and the person with dementia with ‘a day at home’ from a care home if appropriate
Introduction

Hull Churches Home from Hospital Services (HCHfH) is a local independent, registered charity in Hull, established in 1993. It provides a range of high quality short-term support services to the people of Hull that include:

- vulnerable older adults on discharge from hospital
- informal carers looking after those with life limiting illnesses at home
- children and families where a parent or carer has been diagnosed with cancer
- Telecare / TeleHealth

HCHfH want to extend their Carers’ Support Scheme so that they can provide support for informal carers caring for people with dementia at home. To ensure that this service is based upon actual need and provides the sort of support that carers really want, the charity carried out a short needs analysis based upon interviews with carers themselves. The charity successfully secured a grant from the Department of Health’s “Reaching out to carers innovation fund 2010/2011” to fund this project.

The part of the project reported here was undertaken by an external consultant commissioned by HCHfH, and consisted of a non-exhaustive literature review, a broad assessment of local dementia services and recorded interviews with a selection of carers. In addition to this work the carers’ support scheme staff undertook to meet with a wide range of dementia services and associated initiatives across health care, social care and the voluntary sector in Hull to provide a more detailed scoping and mapping of current provision and to network with local providers. They also made enquiries to evaluate current trends, initiatives and best practice regarding dementia care education to inform their dementia education programme for volunteers and staff. They also investigated further the range and scope of assistive technologies pertinent to dementia care. These findings are reported elsewhere.

This report starts by giving a brief overview of the causes, occurrence and nature of dementia and providing some national and local context for people living with dementia and their informal carers. The literature reviewed comments upon the nature and needs of informal carers caring for someone with dementia and identifies current best practice themes in dementia care and in the care and support of informal carers.

Relevant current health and social care policy is identified and local interpretation, implementation and progress regarding these are discussed. Workforce and service provision issues are highlighted.
About Dementia

‘Dementia’ is an umbrella term. It is used to describe the symptoms that arise because of loss of brain function that occurs when the brain is affected by certain diseases or conditions. The loss of brain function is usually progressive and eventually severe.

Other terms commonly used to denote this loss of brain function include “being senile”, “having Alzheimer’s” or “having memory problems”.

Dementia is acknowledged as a devastating disease, a thief that “steals away the people we care about”(Valerie Wood cited in an NHS Hull press release September 2010). The loss of personhood associated to dementia is widely acknowledged and greater awareness and understanding of this has led to a shift in the paradigm of dementia care from a narrow focus on symptom management to care that acknowledges the therapeutic necessity of addressing the psychosocial aspects of the disease (Kelson 2006). The persistence of self in those with dementia is also recognised (Harrison 1993). Personhood is more than just cognitive ability, and demonstrations of self are not only determined by memory - linguistic, visual and emotional recognition are also of great significance (Fazio and Mitchel 2009).

Steve Iliffe and colleagues (2006) identify a particular lack of understanding of psychosocial interventions for dementia in primary care. Esme Moniz-Cook (2010) identifies a reliance on pharmacological management, particularly antipsychotics, in care homes and a similar lack of understanding and implementation of psychosocial interventions. Iliffe et al (2006) suggest that “The pervasive tendency to frame the tasks of dementia care in terms of a medical management model brings responses that can undermine the view that people with dementia may in fact have a tractable disability”. Many individuals with dementia “have complex needs which, if unmet, will continue to hamper the vision of the National Dementia Strategy (NDS) and its goal to enable people to 'live well with dementia' (Department of Health, 2009a)” (Moniz-Cook 2010).

Causes of Dementia

“The most common diseases which give rise to dementia are Alzheimer's disease, vascular dementia and dementia with Lewy bodies” (Alzheimer’s Society 2011).

Other rarer causes of dementia include:

- Fronto-temporal dementia (including Pick's disease)
- Progressive supranuclear palsy,
- Korsakoff's syndrome
- Binswanger's disease
- HIV and AIDS
- Creutzfeldt-Jakob disease (CJD)
- Multiple sclerosis
- Motor neurone disease
- Parkinson's disease
- Huntington's disease
Mild Cognitive Impairment
Mild Cognitive Impairment (MCI) is when the symptoms of memory problems “are not considered severe enough to warrant the diagnosis of Alzheimer's disease or another type of dementia. ...... Recent research has shown that a small number of individuals with MCI have an increased risk of progressing to Alzheimer's disease. However, the conversion rate from MCI to Alzheimer's is small (10-15 per cent), so a diagnosis of MCI does not always mean that the person will go on to develop Alzheimer's” (What is Dementia - Alzheimer’s Society 2011).

Cognitive Impairment and Parkinson’s Disease
Most people with Parkinson’s Disease (PD) suffer from some cognitive impairment (Goldman Gross et al 2008). In the early stages of the disease this is usually mild but some people do have more significant problems with memory, attention, or planning. This impairment can sometimes be exacerbated by the medications used to treat PD. Research suggests that as PD advances so does the occurrence and severity of the cognitive impairment; it is estimated that between 20% and 40% of those with advanced PD will develop dementia. However, research also suggests that motor impairment itself does not appear to be a reliable predictor of subsequent dementia (Verbaan et al 2007). Life expectancy for someone with Parkinson's Disease is only slightly lower than the national average; many doctors estimate this difference to be no more than 5 years.

Deprivation and Dementia
Statistics show that Hull City Council is the 11th most deprived local authority (out of 354) in England, and is in the bottom 10 - 20% deprived nationally in most domains. However, there have been some measurable improvements, especially regarding employment and health, since 2004 (Source: Hull City Council 2011 www.hullcc.gov.uk).

Deprivation is associated to greater occurrence and co-occurrence of a range of disease risk factors including risk factors for atherosclerosis, which is a known risk factor for vascular dementia. It is, therefore, suggested that vascular dementia may have a social disadvantage profile similar to that for atherosclerosis. Approximately 50% of all cases of dementia have a vascular component (i.e. vascular dementia or mixed dementia).

Known risk factors for atherosclerosis include:
- diabetes
- obesity
- smoking
- drinking too much alcohol
- lack of exercise
- eating a high-fat diet

"Investment is needed in local public health campaigns to reduce people’s risk of developing dementia in later life by encouraging healthy eating, physical activity, mental exercise and social stimulation. What’s good for your heart is also good for your head” (YHIP 2010a p 9).

Primary prevention activities and disease risk programmes e.g. the cardiovascular disease (CVD) risk programme, will need to reflect and include prevention of vascular dementia.

Complex Needs and Life Expectancy for People with Dementia
Dementia is a life-shortening illness but the life expectancy of a person with dementia is unpredictable; disease progression may continue for ten years or more and the person may ultimately die as a result of complications of end stage dementia, from another illness such as cancer, or from another condition or illness (e.g. bronchopneumonia), though dementia may be
an exacerbating factor. The Alzheimer’s Society recommendations regarding the National End of Life Care Strategy for Adults (2006) suggest that the median life expectancy for someone with Alzheimer’s disease is about 8 years from onset of disease, but people can live as long as 10-15 years post diagnosis. A third of patients between 75 and 85 with mild to moderate disease will die within a year.

Research funded by the Medical Research Council (MRC) (Raite et al 2010) suggests that people aged 60 to 69 survive 6.7 years after being diagnosed with dementia by their GP, whereas those identified by an active screening programme e.g. a memory assessment service, survive 10.7 years. They also comment that the risk of death was highest in the first year after diagnosis which “may reflect diagnoses made at times of crisis or late in the disease trajectory” (p1).

Dementia is associated with complex needs and high levels of dependency and morbidity (NICE 2006). This has a huge impact on individuals and their families but also on health and social care resources (Raite et al 2010).

People with dementia are at increased risk of physical health problems, this is in part because particular dementias (e.g. vascular dementia) are associated to other severe illnesses such as stroke or Parkinson’s disease (NICE 2006). Research also shows that patients with advanced dementia who suffer acute illnesses, e.g. pneumonia or a hip fracture, have a very poor prognosis and survival compared to their cognitively intact counterparts (Morrison and Siu 2000). In dementia sufferers men, older people, and those with pre-existing comorbidities show decreased life expectancy and survival (Raite et al 2010); however, Raite et al (2010) also suggest that life expectancy may predominantly be determined by an individual’s dementia rather than by comorbidities.

**Prevalence of Dementia**

Dementia is considered a common condition; the NHS states that in England alone 570,000 people are living with dementia, and this figure is expected to double over the next 30 years (NHS Choices - accessed March 2011). “This corresponds to a population prevalence for England of 1.1%; currently a large proportion of these people are likely to be undiagnosed” (NICE 2010a).

The annual incidence of dementia in the English population was estimated, using 2005 figures, as 0.31%, and represents the proportion of the population that is likely to develop dementia within 1 year. Recent research (Raite et al 2010) states that the incidence of “recorded dementia” had not changed between 1990 and 2007.

Dementia is associated to older age, i.e. 65 or over; it is not an inevitable consequence of ageing, but the likelihood of developing the condition increases with age. Dementia is slightly more common in women than in men (NHS Choices - accessed March 2011).

Prevalence of dementia is higher in older age - 1 in 5 men and 1 in 4 women aged 85 and over; age also affects the severity of dementia, with more incidence of moderate and severe dementia in those aged 85 and over compared to younger age groups. However, ‘early onset’ dementia is also evident, with an estimated 16,000 people in the UK under the age of 65 with the condition; though this thought to be an underestimate (Alzheimer’s Society 2011). Raite et al (2010) confirms that incidence is “higher in women and in younger age groups (60-79 years) living in deprived areas” (p1).
Demographics

Older population
In the UK we have an increasing population but in particular an increase in the older population - more people are living into old and even into extreme old age (i.e. over 90).

In Hull life expectancy at birth is approximately 75 years for men and 79½ years for women, which is between 2½ and 3 years below the average for England.

In 2009 it was estimated there were 42,700 residents of retirement age in the City (16.3% of the total population), with approximately 9,900 residents aged 80 or over (3.8% of the total population).

Whilst these figures are about 3% lower than the average for England projections suggest the local older population is increasing. It is estimated that a 41.5% increase in the population of people aged 60 and over is expected in Hull by 2033 to 69,900 residents and nearly a 73% rise in the number of residents over 80 to 17,100.

It was estimated in 2008 that 8,477 people over 65 in Hull had a life limiting long term illness and lived alone, it is suggested that this will increase to 9,900 by 2020 (Hull Link – Extra Care Strategy 2009).

Dementia Demographics
The report “Dementia in Yorkshire & Humber a Demographic Profile” (Jackson 2009) published by the Yorkshire & Humber Improvement Partnership (YHIP) suggested that the number of people in Hull with late onset dementia (over 65) in 2009 was 2,523 and predicted this figure would rise to 3,304 by 2025 (31% increase). In 2008 it was estimated that 59 individuals in Hull had early onset dementia (under 65) and predicted this would rise to 72 by 2025.

About 120,000 people in the UK have Parkinson’s Disease (PD) (approximately 1 in 500 of the general population or 1% of individuals older than 60 years); in Hull with an estimated population of 262,400, this could mean 525 individuals. Approximately 24 to 31% of these will have dementia (i.e. up to 162 individuals). Research suggests that 3 to 4% of the dementia in the population would be due to PD (Aarsland et al 2005).

Assuming the above data from the YHIP report includes individuals whose dementia is due to PD and allowing for a 2% increase since 2009 this would suggest that in total approximately 2,630 people in Hull have some form of dementia today.

NHS Hull state that about 900 people in Hull currently have a dementia diagnosis (34% of the estimated dementia population), they suggest there are probably at least that number again living with the condition but don’t know about it (NHS Hull 2010), or have not sought a diagnosis. This correlates quite well with the YHIP report estimates that suggest that on average in the region just 40% of those estimated to have dementia are on GP registers with a dementia diagnosis - in Hull this would be just over 1000 people.

The YHIP report also states that the majority of the remaining 60% “are not supported by clinical services” but “may have the mild form of the condition and therefore might require a
more “light touch” service than those currently known to clinical services - e.g. provision of information, advice, counselling and lifestyle tips (Jackson 2009). This illustrates “the gap between the known cases and the undiagnosed cases of dementia - for every two people diagnosed with dementia in the Yorkshire & Humber region, there are likely to be three others unknown to the clinical services” (Jackson 2009 p12).

The Alzheimer’s Society suggests that in the UK one third of people with dementia in the UK live alone (Jarratt 2010); in Hull this could equate to over 870 individuals. As expected the number of people with dementia living in the community increases with age (Jackson 2009).

In 2008 it was estimated that in Hull 919 individuals with late onset dementia were living in some form of care home, with predictions that this would rise by 35% to 1,238 by 2025 - an extra 319 places (Jackson 2009). Nationally, the prevalence of dementia differs between residential care settings - “[prevalence of dementia in] care homes for the Elderly Mentally Ill (EMI) was 80%, in nursing homes was 66% and in residential care home was 50%”, and the proportion of people living in care homes with dementia increased significantly at age 85 and over (Jackson 2009 p23).

**Vulnerable and disabled adults**

Increased life expectancy is also now being enjoyed by many vulnerable and disabled adults. Whilst the life expectancy of those with more severe levels of disability are still reduced compared to the general population, life expectancy does on the whole increase as the level of disability reduces. The shift in life expectancy evident in the general population is reflected to some extent in the mean life expectancy of people with learning disabilities, with estimates that the proportion of people with learning disabilities over 65 years of age will have doubled by 2020.

However, life expectancy of people with Down’s syndrome (estimated mean 55 years (Holland et al 2000) cited by the British Psychological Society (BPS) 2009) remains reduced compared to the general population, but this population is also at increased risk developing dementia with increasing age, compared to the general population. This risk can start in their 30s and steadily increases in prevalence with age and can be evident in up to 50% of individuals aged 50 to 59 years (BPS 2009). “The prevalence of dementia in people with other forms of learning disability is also higher than in the general population”, perhaps up to 4 times higher:

- Aged 50 years and over: 13 per cent
- Aged 65 years and over: 22 per cent.

(Source: Learning disabilities and dementia - Alzheimer’s Society (2010))

The Hull Learning Disability Partnership Board (HLDPB) acknowledges that “Not enough is known about how many people with a learning disability there are in Hull and what sort of disability they have” (HLDPB 2009). Based on national estimates it is suggested that there could be 3,914 adults with a learning disability in Hull, 974 of whom would have a severe level of disability (Hull Link 2009).

For the Yorkshire and Humber region numbers of people predicted to have Down’s syndrome and dementia are small, 177 for 2010 rising to just over 200 in 2025 (Jackson 2009). The YHIP report acknowledges that relatively small numbers may be subject to larger levels of sampling error, and so local authority figures are not provided.
The Carers

People with dementia are often old and frail and family carers, commonly a spouse, are also old and frail themselves. “The strain of caring for someone with dementia can cause physical or mental illness in the carer” (NICE 2007). Up to a third of these carers are depressed and caring can also reduce their life expectancy. Older carers supporting a spouse, living with the “care recipient” and reporting “caregiving strain” are 63% more likely to die within 4 years than non-caregivers (Shultz and Beach 1999 p2218).

As the disease progresses behavioural and psychiatric disturbances can emerge that cause behaviour that challenges. These symptoms are frequent and difficult to manage and cause the individual and their families/carers great distress. “The most dominant causes of stress in carers are psychiatric symptoms and behavioural disturbances in the person with dementia (which may be even more common in younger people with dementia), and not the degree of cognitive impairment or difficulties with activities of daily living” (Alzheimer’s Scotland 2003).

“Care needs often challenge the skills and capacity of carers and available services” (NICE 2007).

NICE (2007) states that “The rights of carers to an assessment of needs as set out in the Carers (Equal Opportunities) Act 2004 should be upheld. Carers of people with dementia who experience psychological distress and negative psychological impact should be offered psychological therapy, including cognitive behavioural therapy, by a specialist practitioner”.

A Carers’ Assessment is an assessment of needs for a person who cares for someone with a disability and provides a substantial amount of care on a regular basis. As a result of the assessment the help provided can be a mixture of personal care (e.g. personal hygiene) for the individual with dementia, emotional support and practical help such as shopping and cleaning (Carers’ Assessment information sheet provided by the Carers’ Centre in Hull (Carers’ Centre 2011- http://carerscentrehull.org.uk/webdocs/docs/pdf/carer%20assessment%20process.pdf). Evidence suggests that a half to two-thirds of all carers do not receive this assessment (Nuffield Centre on Bioethics 2009).

However, research also suggests that “Older couples should be evaluated as a unit, both in terms of their health status as well as the caregiving demands that exist in the home environment” (Shultz and Beach 1999 p2219). These researchers suggest that any interventions developed should focus on the needs of both individuals simultaneously. This is supported by other work that acknowledges that a health and social care service delivery model predicated on an exclusive focus on the patient or client “may not be appropriate in dementia care, at least at some stages, where the major part of the care is delivered by the family or other carers” (Nuffield Centre on Bioethics 2009 p118). Families should be regarded “as ‘partners in care’, reflecting the solidarity shown with the family” Nuffield Centre on Bioethics 2009 pxix).

Late stage dementia brings with it a host of issues and is especially challenging even for those who have been caregivers for many years. At this stage the patient is usually bedbound, cannot communicate verbally and is completely dependent upon “sensitive caregivers to advocate, connect, and attend to her needs” (Wayne 2009). Though caregivers may want to keep their loved at home the needs associated to advanced illness and physical safety and the demands and stamina required to provide 24 hour care need to be carefully considered, and will require considerable support from others. This may be the prompt or ‘tipping point’ for placement in a care home.
It is also recognised that “Many carers continue to see themselves as carers even when the person with dementia has moved into a care home, right up until the person with dementia dies” (Nuffield Council on Bioethics 2009 p117).

**Caregiver Burden**

Dementia is a very personal journey for both the person with dementia and for their family and carers, and no two journeys will be the same (NHS Education Scotland 2009). Though there may be similarities, there are also wide variations in carers’ circumstances, needs, and preferences and in the disease trajectory of the person they are caring for.

Whilst the carer will usually know the person they are caring for better than anyone else, they are often unaware of the nature and progression of dementia or what care and support may be needed or are available (Nuffield Centre on Bioethics 2009).

Research shows that prior to a dementia assessment and diagnosis, older people (including carers) consider their lives as “having purpose, meaning and pleasure for themselves and others”. They associate dementia with loss of mental and physical ability that will damage their relationships and quality of life (Moniz-Cook et al 2006a, 2006b). Early interventions that include information and psychosocial support for the person with dementia and their carer/family are recommended.

Evidence demonstrates that interventions aimed at individual carers and families do help to significantly reduce carer stress, especially if implemented early and maintained. Carers’ stress is associated with poor mental and physical health; it can impact on the quality of their relationship with loved ones (including the person they are caring for), can negatively affect their ability to continue in their caring role, and can precipitate residential care placement for the person with dementia. It is also suggested that the extra financial costs that may be associated to caring for someone with dementia can be substantial, including for some a significant loss of earnings (Quince 2010).

Research indicates that in early dementia assessing cognition of the person with dementia is not an accurate indicator regarding caregiver burden, deterioration in carer mood and increased carer stress (Richards et al 2003). Following nearly 400 individuals with dementia over a 12 month period showed that whilst their cognition remained stable the frequency of day-to-day problems increased - thus increasing caregiver burden. This indicates that assessment of cognition needs to be supplemented with assessment of ‘psychosocial disability’ to enable a more comprehensive assessment of caregiver burden.

**What services do carers need?**

One of the key messages is that one size does not fit all – services provided for carers must be varied and must also be flexible, in order to be able to respond rapidly to changes to carer’s needs - which are often as a result of sudden changes in the needs of the person they are caring for.

Alzheimer’s Scotland (2003) says that “The full range of resources that should be made available include:

- Assessment
- Information
- Early support and counselling
• Education and training
• Therapeutic interventions for challenging behaviour
• Carer support groups
• Advocacy services
• Short break/respite care
• Day care and day opportunities
• Home support services
• Environmental approaches and crisis intervention services”

The Scottish Executive and Alzheimer Scotland (2004) also point out that services should be available round the clock, every day.

The aim of interventions and resources for carers for people with dementia have been defined in one Scottish NHS publication (1997) as:

• Enabling carers to continue caring for the person with dementia in their own home for as long as practical
• Enabling carers to maintain a caring relationship between them and the person with dementia
• Enabling carers to feel fulfilled and satisfied in their caring role

A more recent policy (NHS Scotland 2005) acknowledges the need for joint services for older people with dementia and their carers with a focus on joint outcomes, which are added to the above and include:

• The ability to live as normal a life as possible, whether in their own home or a care home;
• Successful re-adjustment to living in their own home when a person with dementia returns from a period of institutional care
• The best possible quality of life for the person with dementia within the limitations of their disability

It is noted that even with the very best support the experience of living with dementia for the individual and their carer(s) and family is highly distressing and difficult. For carers it is often difficult to know how best to respond and there is often potential for conflicts of interest, some of which can be serious, between the person being cared for and their carer(s) and family (Nuffield Centre on Bioethics 2009 p18). For health and social care practitioners there is also a constant balancing act necessary - between enabling people with dementia to ‘live well’ by supporting the individual’s autonomy and well-being and addressing the interests, concerns and needs of carer(s) and family, as they are integral to that ‘living well’ (Nuffield Centre on Bioethics 2009).

Accessing Services

The literature also raises questions as to whether help and support is sought by carers, for themselves or the person they care for, in a timely fashion. It is recognised that carers may not seek help as early as they might, as it takes some time for them to realise they are not coping and may see seeking help as an admission of failure. It is also suggested that accessing help may not be straightforward “because of a lack of knowledge about how the ‘system’ works” (Nuffield Centre on Bioethics 2009 p 122).

The notion that services may not be accepted when offered, is also highlighted, and that this refusal can lead to increased caregiving burden and ultimately to abuse and neglect (Gainey et al 2010). However, contact with specialist services alone may not be sufficient to reduce or
prevent abusive behaviour and additional psychological support that addresses carers depression and anxiety may also be needed (Cooper et al 2010).

Anecdotally it is suggested that services offered may not be accepted due to how the individual views their caregiving role (e.g. as their sole responsibility), or perhaps that they do not really view themselves as a carer, and that the care they provide is a part of the relationship they have with the cared for individual (e.g. spouse, child, parent). For some it may also be an unwillingness to accept the reality of the diagnosis, and for others it is can be regarding perceptions and experiences of shame and stigma that they associate to either the diagnosis or the need to accept help from statutory services. This also suggests that individual characteristics - personality and understanding - impact upon acceptance of services and this may be independent of their social context.

Another view offered by Gainey et al (2010) is that the social context of the caregiving experience influences the acceptance of services. They agreed with existing research that generally in disadvantaged communities there are often lower rates of service utilization and that this is in part related to how carers view their caregiving role, together with personal traits. Gainey et al’s (2010) work, though it has limitations, showed that if the person being cared for has dementia as well as the care being provided in a disadvantaged community then it is even more likely to result in a refusal of services. They also found that refusal of services “is more likely among females and in neglect cases”. The reasons for this, they suggest, are similar to issues of self-neglect, mainly social isolation - “diffuse and weak connections” to any social networks or local community. They suggest that community based initiatives that support care services and promote social integration and services that provide an accessible ‘one stop’ gateway for both carers and those with dementia to access services are recommended.

**Psychosocial and Practical Support**

Social isolation for carers and the person with dementia can be a significant problem. The Partnerships for Older People Projects (Popps) in Bradford (2010) identified that this can come about as a result of:

- Increased need for supervision and the associated lack of spare time for the carer
- Isolation of the carer due to the care receiver’s behaviour problems

They also identified that caregiver burden is increased because of:

- Limited ability of the care receivers to express gratitude and the associated reduction in uplifts of care giving
- Progressive deterioration of the care receiver, which reduces visible positive long-term rewards for the carer’s engagement

To address these issues they (Popps Bradford) identified what worked for carers of people with dementia:

- Long-term, intensive and comprehensive relationships between carers and support services
- Memory clinics
- Residential programmes
- Family counselling and support
- Meeting Centres
- Befriending services for carers based on social support

The project introduced for carers of people with dementia:

- Wellbeing Cafes
• ‘Health in Mind’ training programme
• Peer Educators
• Intensive Home Treatment teams

They also commissioned Relate Bradford to run a series of outreach clinics across the district and provided follow-up support through free relationship and family counselling. Whilst all the elements evaluated well and showed improvement in carers’ well-being and coping overall, it was also established that there was a huge need for some direct form of additional support, such as respite or sitting services (Windle et al 2009).

The impact volunteers can have on social isolation especially through providing support in a person’s own home is well recognised. Bowers et al (2006 p6) remark that “Vitally, volunteers help to reduce isolation and loneliness for many of the people they support through the human contact they provide and the social interaction that results – which is often otherwise very limited. Over two thirds of the volunteers who took part in the postal survey emphasised that the most important thing they provide is emotional or personal support, often described as a ‘listening ear’ or ‘social visits’”

Peer Educators and ‘Expert’ Patient and Carers
The role of peer educators, expert patients and expert carers is well established in health care today, and is recognised as a central principle to good chronic illness care (World Health Organisation (WHO) 2004), as a means of delivering health and social welfare information (Peel and Warburton 2008) and a means of contributing to professional education (Lomas 2009, Dementia UK 2011). It will contribute to effective self-management, health promotion and effective advocacy, and can help improve cultural sensitivity and reduce health inequalities (d’Elia et al 2009). It is seen by WHO (2004) as one of the 10 key principles for managing chronic illness and risk conditions; the 10 principles are (p5):

1. Develop a treatment partnership with your patient.
2. Focus on your patient’s concerns and priorities.
3. Use the 5 A’s: Assess, Advise, Agree, Assist and Arrange.
5. Organise proactive follow-up.
6. Involve “expert patients,” peer educators and support staff in your health facility.
7. Link the patient to community-based resources and support.
8. Use written information - registers, Treatment Plan, treatment cards and written information for patients - to document, monitor and remind.
9. Work as a clinical team.
10. Assure continuity of care.

Spending Time Together and Apart
Respite defined by the Alzheimer’s Society as “short-term care used as a temporary alternative to a person’s usual care arrangements”, can include care at home or away from home. Each of these may have an important role to play in the health and wellbeing of both the carer and the person being cared for, but may not be appropriate for everyone.

For couples it is often equally important to also have ‘respite’ together, a short term break from the day to day roles and routines for the carer and cared for; being supported to do things together, to have their relationship as a couple acknowledged and to be treated as a unit are considered very important to some. Equally, being supported to have time together with the wider family and circle of friends is also important.
Many carers also recognise that some of the ‘personality’ changes attributed to the dementia can sometimes be a result of depression, boredom, frustration, misunderstandings and feeling overwhelmed by what seem unfamiliar surroundings and what are now difficult tasks. They want active help and support that will stimulate the lives of the person they are caring for as well as providing stimulation in their own lives. Couples also recognised the need for ‘a safe place’ - a friend, a support group, a helpline, a confidential internet chat-line, a counsellor - “in which to air emotional issues affecting their relationship”.

Having the opportunity to address the changes in sexual intimacy in their relationship is important to many couples – but is regarded as “an enormous challenge, especially as the needs of both partners must be considered”. Effective communication is essential (Alzheimer’s Scotland 2003) but sometimes it is difficult to achieve and may need to be facilitated.

This is supported by a holistic approach to health and wellbeing and a person centred rather than disease centred approach to care and support.

**Holistic Models of Wellness**

The Wheel of Wellness is a holistic model, of which there are now many variations, all of which have been derived from the original work by Sweeney and Witmer (1991 and 1992). It often used to help provide psychological support to the individual with dementia but can also be applied to the carer and to the care context - e.g. the couple as a unit.

“Wellness has been defined as a new paradigm in health care (Larson 1999), as a strengths-based approach to mental health care (Smith 2001), and as the paradigm for counselling and development (Myers 1992)” (Meyers and Sweeney 2005 p269).

The Indivisible Self: An Evidence-Based Model of Wellness has emerged most recently from this work (Meyers and Sweeney 2005). This comprises of one higher-order wellness factor - ‘Self’, or the ‘Indivisible Self’ and 5 second order factors which comprise the ‘Self/Indivisible self’ - the five factors are ‘Essential Self’, ‘Social Self’, ‘Creative Self’, ‘Physical Self’ and ‘Coping Self’.

Each of the 5 factors have different components:

- **Essential Self** - spirituality, self-care, gender identity, and cultural identity.
- **Creative Self** - thinking, emotions, control, positive humour, and work
- **Coping Self** - realistic beliefs, stress management, self-worth, and leisure.
- **Social Self** - friendship and love.
- **Physical Self** - exercise and nutrition.

These coexist in a context of variables that include:

- **Local (safety)** - Family, neighbourhood and community
- **Institutional (policies & laws)** – Education, religion, government, business/industry
- **Global (world events)** – politics, culture, global event, environment, media, community
- **Chronometrical (lifespan)** – Perpetual, positive, purposeful

This model, it is suggested, “provides a foundation for evidence-based practice for mental health and counselling practitioners. It is based on characteristics of healthy people and thus can be considered to be strength based; it is choice-oriented in that wellness behaviours reflect intentionality in lifestyle decisions; and it is theoretically grounded. Practitioners can use the model……to help clients understand the components of wellness, the interaction of those components, and the manner in which positive change can be created through a focus on strengths as opposed to weaknesses” (Meyers and Sweeney 2005 p277).
Health and Social Care Policy
Dementia care in the UK is driven and directed nationally and locally by a wide range of health and social care policies, as shown in the list below. Of these, the National Dementia Strategy (DH 2009a) is a key document that is directing local service development.

Whilst policy aspiration is to integrate health and social care policy, services and funding, this has yet to be reflected in practice (Ham 2009). The considerable change and reform that health and social care is undergoing, especially regarding commissioning and delivery of services, presents service providers, including providers of dementia services, with a number of challenges. However, it is also suggested that equally a number of service delivery opportunities will also emerge, especially for the community and voluntary sector (Sachrajda 2011).

Health and social care policy relevant to dementia care
- Disability Discrimination Act (DDA)1995 *see comment below
- The Human Rights Act 1998
- Mental Health Capacity Act (2005)
- Putting people first: a shared vision and commitment to the transformation of adult social care (DH 2007)
- Dementia. Supporting people with dementia and their carers’ in health and social care (NICE 2006, updated in 2007, review decision date: November 2011)
- High quality care for all: NHS Next Stage Review - final report (Darzi Report (DH 2008))
- Health and Social Care Act (2008)
- End of Life Care Strategy (DH 2008)
- Carers at the heart of 21St century families and communities (HMSO 2008)
- Living well with dementia: A National Dementia Strategy, (DH 2009)
- Living well with dementia: A National Dementia Strategy Implementation Plan (DH 2009)
- End of Life Care for people with dementia Commissioning Guide. Implementing NICE guidance(NICE 2010)
- The NHS White Paper: Equity and Excellence: Liberating the NHS(DH 2010)
- Disability and the Equality Act (2010) *(From 1 October 2010, the Equality Act replaced most of the Disability Discrimination Act (DDA). However, the Disability Equality Duty in the DDA continues to apply).

The National Dementia Strategy
The National Dementia Strategy (DH 2009a) has 3 key steps to improve the quality of life for people with dementia and their carers:
1. Ensure better knowledge about dementia and remove the stigma
2. Ensure early diagnosis, support and treatment for people with dementia and their family and carers
3. Develop services to meet changing needs better

The Strategy lists 17 key objectives to be achieved; in Hull, 4 of these 17 objectives have been prioritised initially. These are:
- good quality early diagnosis and intervention for all
- improved quality of care in general hospitals
- living well with dementia in care homes
- reduced use of antipsychotic medication
“Early diagnosis and intervention improves quality of life through enabling people with dementia to access suitable support services and to delay or prevent premature and unnecessary admissions into hospitals or care homes” (YHIP 2010a p13).

The Personalisation Agenda in Health and Social Care

Nationally

Launched in December 2007, it was expected that significant progress would be evident in the personalisation agenda by March 2011 (DH 2007a p5).

“Personalisation is about giving individuals more choice and control over their health and social care support, to better support independent living and social inclusion” (Loul and Crawshaw 2008). It is recognised that personal budgets (including direct payments), which are funded through social care can improve satisfaction with care (Poll et al 2006, Hatton et al 2008 SCIE, 2010). The common assessment framework, direct payments and self-directed care are central to this; the person in need of care (health or social care) decides what type of support they will receive, who from, where and when. However, the method of social care funding in the future remains uncertain until the findings of the Dilnot Commission on Funding of Care and Support are published in July 2011 (Sachrajda 2011).

Personal budgets have been seen to impact positively upon where someone lives, who they live with, what they do with their time and who supports them (Poll et al 2006). However, the Alzheimer’s Society suggest that the evidence to support how to make this agenda work for people with dementia and their carers is limited. They state that “significant steps are needed to enable individuals to take advantage of the system. It is also important to recognise that some people will either not be able to make use of this system, or will not want to” (Lakey 2011). Current research indicates a number of limitations of personalisation for those with dementia and their carers - due to their poor awareness of the personalisation agenda, the onerous nature of the assessment process, and the unpredictable nature of the illness, resulting in:

- Poor access and professional gatekeeping
- Poor uptake of direct payments
- Poor effectiveness of personal budgets

In dementia early diagnosis and early intervention are closely associated to effective personalisation.

It is also acknowledged that this agenda requires a major culture change for care providers and this shift from a traditional service-led approach towards an integrated whole person, person centred approach presents significant challenges to the current organisation of the NHS and social care (Alakeson 2011).

A key element of this agenda for carers is the carer’s assessment, but as stated earlier a half to two thirds of all carers do not receive this assessment (Nuffield Centre on Bioethics 2009).

Personalisation in Hull

Information regarding Hull’s most recent progress towards the personalisation agenda is not readily available nor are statistics regarding carers’ assessments, direct payments and personal payments to date. However, Hull is also a full pilot site for the Personal Health Budgets Pilot programme launched this year (2011), which includes direct payments. The pilot scope includes long term neurological conditions, COPD, diabetes, NHS continuing healthcare and end of life care and runs until 2012.
Results from personalisation agenda update events held in Hull in June and December 2009 indicated that the transformational changes in social care introduced uncertainty, which I suggest compounded today with the fundamental changes in health care commissioning and service delivery. Hull City Council said that whilst there was a commitment to change, exactly what the future would look like would “be dependent on developing trends amongst service users or customers themselves”; they also suggested that it was difficult to determine the future of third sector commissioning (Hull Link 2009) because of this uncertainty. Services users at the events said that as the local personalisation agenda progressed they wanted to see:

- More accessible information to be available to service users in relation to how to access services, the services available and general guidance as to how the system works.
- Greater advocacy provision for service users.
- Greater partnership working with voluntary and community organisations (VCO) to provide a complete range of services.

The YHIP Regional Review of Dementia, City of Hull Locality Report (Brown 2009) states in their executive summary that “the numbers with dementia holding actual budgets is unknown. Most carers reported having little knowledge of the scheme and once explained, some expressed anxieties about the responsibilities associated with them.”

Nationally there is some concern expressed regarding third sector organisations: “the third sector is not yet ‘ready’ for the personalisation agenda” (Dickinson and Glasby 2010 p14) and “are not sufficiently engaged .....to respond effectively”. This fundamental lack of understanding regarding the key debates around personalisation Dickinson and Glasby (2010) suggest, may mean that third sector organisations are unable to support service users and their carers.

In Hull it is recognised that the personalisation agenda is still in development and a partnership approach that includes local VCOs is needed. However, locally VCOs are already involved in the delivery of direct payments and payroll services linked to personal budgets. Within the city a personal assistant recruitment service has been developed and work to develop VCO capacity is underway. HCHfH is very well apprised of its role and future potential in the personalisation agenda through all its services and its collaborative and integrated approach; this recent dementia project is a direct result of this awareness. HCHfH has an excellent track record for vision and innovation and articulate very clearly their current provider role with regards to personalisation, but also recognise their role as an educator and advocate for users and their role in positively influencing service development and delivery to help ensure services “that are nearer to what service users and their carers want and need.” (Dickinson and Glasby2010 p24).

**Current Service Provision for Dementia**

Hull is like many other cities when it comes to its dementia care services. The following quote from a strategic model of care and clinical strategy document produced for Sandwell and the Heart of Birmingham (Birmingham Metropolitan Council et al 2010) could just as easily be describing current services in Hull:

“Dementia services currently cut across Mental Health Services and Older People services alongside Primary Care, Social Care, Acute care, Care Homes, and the Independent, Charity and Voluntary sectors.

Funding sources vary and there is no overarching coordination of services for people with Dementia across their disease journey.
Links between services for those with Dementia who have other long term conditions or general increasing frailty are poor and the staff are generally ill equipped to address behavioural changes in general settings and physical issues in mental health settings.

There are pockets of innovative developments in parts of service provision.

On their own these are insufficient to address the existing issues but could be strengthened as part of a more cohesive, seamless and proactive strategic approach to Dementia care.

There is a local recognition that health and social care aspects are equally important.

There are different skills in different organisations and a reliance on the level of provision from the community and voluntary sectors.

There is a real need for competent staff, educated and trained on an on-going basis who feel as though they work as part of a wider team of staff providing a high quality Dementia service no matter the organisation they work within.

There is a dynamic which must be managed between the Health and Social Care Act (2008), which focuses on safety and quality, and the ‘Putting People First’ (2007) and Personalisation agenda, which emphasises the rights of individuals to have choice and control of their care and support.”

In Hull innovative developments include the Hull Memory Clinic and their stepped approach to care (YHIP 2010b), and some new roles and services have been implemented such as dementia leads, nurse specialists (e.g. Admiral Nurses) and planned new services (e.g. outreach services from the Alderson Resource Centre).

**Strategy Implementation and Workforce Issues**

In 2006 Iliffe et al stated that “The existing workforce in health and social care in the UK is already too small to implement all of the changes required by the National Service Framework for Older People and National Service Framework for Mental Health. This has clear implications for the labour-intensive work of dementia care.” Unison (2008 p4) express in their Response to the National Dementia Strategy consultation a similar concern “in recent years there has been a significant reduction in the number of overseas recruits [to nursing] The worsening exchange rate (sterling compared to both the Euro and US dollar) means there will continue to be a fall, and this combined with an aging nursing workforce is going to put a severe squeeze on the nursing workforce.”

In 2009 the All-Party Parliamentary Group (APPG) on Dementia produced a report ‘Prepared to care. Challenging the dementia skills gap’ (APPG Dementia 2009).

The executive summary highlighted the following issues:

“As a whole, the social care workforce has a very limited knowledge of dementia and is therefore not ready to provide high quality dementia care. There are some examples of
excellent practice demonstrating that, given the right support, staff can improve quality of life for individuals with dementia” (p.xi).

“Although training alone is insufficient to improve the care provided to people with dementia, ... it would not improve the quality of life for people with dementia in organisations that did not value good care....” but “very low level of training in dementia is a significant barrier”(p.xi).

“Funding problems are also perceived to be a barrier to workforce development. Not just because of the cost of training, but also because budgetary restrictions lead to poor practice such as 15 minute home care visits” (p.xii).

A recent report on Mental Health Productivity by the Kings Fund (Naylor and Bell 2010) highlights the following issues:

- There is considerable underfunding of older people’s mental health services
- Patients in general hospitals were significantly more likely to experience discharge delay if they had dementia - more than two-thirds of patients with dementia were assessed as no longer needing to be there
- The National Audit Office (NAO 2010) has been critical of the limited progress made in implementing the national dementia strategy to date. Key problems appear to be:
  - limited local leadership
  - lack of co-ordinated working between health and social care services
  - inadequate training, resourcing or performance monitoring to support implementation
- There is considerable scope to reduce costs by providing specialist input into care homes, A&E departments and acute wards, and by providing access to crisis resolution and home treatment (CRHT) services (Anderson et al 2009).

In addition, the health and social care workforce have to adapt to the challenges of the personalisation agenda: ‘the vision for a personalised approach to adult social care has huge implications for the workforce of the future’ (DH 2008). One challenge, it is suggested, is to build a confident professional workforce that retains its identity (Goodburn2009). Another challenge is to ensure a common understanding of personalisation and develop an integrated approach whilst also ensuring clear independent understanding by health and social care providers of what ‘personalisation’ means to their service and what, for instance, might be ‘bought’ with a personal ‘social’ or personal ‘health’ budget.

This agenda presents implications for some staff in particular - e.g. the role of care co-ordinators and social workers has been ‘turned on its head’ (Glendinning et al 2008). More Personal Assistants (PAs) will be needed, and in addition to traditional recruitment and training issues in today’s financial climate, new issues regarding supervision, management and quality will need to be addressed as PAs can be employed directly by the person they support, by an agency/organisation, or be self-employed. PAs will, therefore, need a wide range of new skills to manage their employment, deliver care and support in a ‘doing with’ rather ‘doing to’ manner as well as ensuring they are flexible, adaptable and responsive to the needs of those they support. Safeguarding is a particular area of concern and balancing risk, personal control, creativity and aspiration is seen as a key challenge (SCIE 2010).
Timely Diagnosis and Intervention

Outside of specialist research facilities “the most accurate diagnosis that can be achieved at present is through a clinical evaluation and diagnosis by an experienced clinician” (Nuffield Council on Bioethics 2009 p17).

“Early diagnosis and intervention improves quality of life through enabling people with dementia to access suitable support services and delaying or preventing premature and unnecessary admissions into hospitals or care homes” (YHIP 2010 p13). Whilst early diagnosis is a recognised policy objective (DH 2009a), in practice this is not always easy to achieve. The primary care professionals (e.g. GPs), who are key to the diagnosis process and subsequent support and management of dementia for many are still often guided by a ‘best interests’ medical model of disability which applies the principle of ‘doing no harm’ and views disabled people as being ‘at risk’, needing to be looked after and to be passive recipients of care. The social model of disability is based upon rights – the right to a diagnosis, information and choice, to be partners in their care from defining the ‘problem’ to agreeing outcomes and choosing the routes and methods of achieving this. Every disabled person is a human being and as such is entitled to be treated equally; risk is ‘risk’ to independence and ‘risk’ to not having access to rights and entitlements.

However, making a diagnosis of dementia is often difficult, particularly in the early stages, and can be confused with the symptoms of other conditions such as depression or anxiety for instance. Individuals who suspect they may have memory problems and/or their family/carers will commonly go to their GP in the first instance and therefore education and awareness for these practitioners is essential, together with an appropriate route to more specialist memory assessment.

Research suggests that there is poor detection and moderate recognition of dementia by GPs (Iliffe et al 2006), but the reasons for this may not simply be related to awareness, knowledge and skills in GPs. Earlier work by Iliffe et al (2003 p378) stated that “practitioners felt inadequately trained for the task of early diagnosis, and that the diagnosis was difficult to accept for professionals as well as patients”. GPs stated they had problems reaching a diagnosis and needed help to do this. They felt it was particularly difficult distinguishing dementia from normal ageing, and they were also very aware of the implications such a diagnosis may have for the individual and their family (Iliffe et al 2003). They acknowledged that they commonly took an opportunistic approach to screening as opposed to a more systematic approach and also claimed that the existing assessment tools such as the mini-mental state examination (MMSE) and abbreviated mental test score (AMTS) were too long for everyday use and were not diagnostic.

A lack of awareness in patients and their families of dementia was also recognised; they may feel that cognitive changes are just part of the normal ageing process, which can lead to non-disclosure of early memory problems and subsequent late presentation (Iliffe et al 2006). Cultural factors could also affect disclosure (Valcour et al 2000). Also carers recognised that to get the person they care for to the point of diagnosis, be that with the GP or referral to a specialist, requires an attitudinal shift from seeing the individual they are caring for “as an autonomous adult to being their spokesperson”. This was a difficult period of adjustment and a difficult decision to make, bringing with it feelings of guilt; it could also be source of conflict with the person they are caring for and the wider family (Livingstone et al 2010 p7).

Lack of continuity of care in a typical GP practice may also contribute to poor detection and recognition of dementia; continuity is an important tool for GPs to recognize cognitive and
behavioural changes in their patients, confirmed by the positive association between the number of previous contacts with the patient and the GP’s diagnostic accuracy (Iliffe et al 2006).

Iliffe et al (2003) suggest that it may be more useful to refer to ‘recognition’ of dementia rather than diagnosis and to relate this to on-going assessment and a continuing relationship, as opposed to diagnosis as a discrete end point. However, whilst a definitive diagnosis of the cause of the dementia may only be confirmed at post mortem (Alzheimer’s Society 2011), there is a need for differentiation between Alzheimer’s disease and vascular dementia to enable drug treatment for the former when appropriate. Education to enable them to make this differentiation may be the ‘help’ that GPs stated they needed regarding diagnosis, but GPs also need to be able to facilitate access to specialist services for their patients through appropriate referral and availability of such services.

A number of reasons are provided in the literature as to why early diagnosis and intervention may not occur (Brodaty 2005, Iliffe et al 2003, Iliffe 2006, Raite et al 2010). These include:

- Individual and family/carers’ unawareness
- Individual and family/carers’ reluctance to seek help
- Dementia not diagnosed in primary care – reluctance to diagnose, poor detection, under-recognition
- Diagnosis poorly recorded – a diagnosis may not be recorded, or non-specific records made (differentiation between Alzheimer’s disease and vascular dementia not made so management impaired, i.e. medication not prescribed)
- Non referral from primary care to assessment and/or other specialist services
- Lack of management plans – treatment emphasis upon co-morbidities
- Late/crisis diagnosis

There is also recognition that there may also be some risks associated to an early diagnosis of dementia (Iliffe et al 2003) and acknowledgement that some individuals and their carers do not always want an early diagnosis, or perhaps any diagnosis. The risks or ‘hazards’ that early recognition of dementia might pose cited below come from 21 workshops conducted in the UK over a 3 month period, with 990 health care, and some social care, professionals including 247 GPs (Iliffe et al 2003 p378).

For the individual and their family the hazards were thought to include:

- Anxiety and fear created by the screening and assessment process as well as the diagnosis “provoking a depressive reaction to the ‘bleak outlook’ ”
- Labelling and stigma that can create shame and isolation and might alter the relationships between the individual and others
- They might “receive a diagnosis when they need a prognosis”

For professionals the hazards identified were:

- Risk of making a diagnostic error and an inaccurate or premature label that could potentially cause damage to the individual, their family and any relationships with their GP
- Impact on service budgets, especially if diagnostic efforts and success increased.
- The pressure that individuals and relatives would exert “on GPs to refer to (already stretched) specialist services or to prescribe expensive anti-dementia medication of uncertain value”
• Iliffe et al (2003 p380) also recognised that “Dementia is one example of a condition that seems potentially to touch the ‘raw edges’ where professional and personal boundaries meet (West 2001)”

Whilst there may be some hazards identified regarding early diagnosis of dementia, the benefits of timely diagnosis and intervention are equally recognised. That recognition of the hazards and benefits of diagnosis by practitioners (Iliffe et al 2003) supports person centred care, as it orientates the diagnosis process on the context of the individual’s life and their relationships. When supported by education, support for all concerned and effective approaches to care, this recognition will impact positively on GPs’ approaches to screening, assessment, diagnosis and communication regarding dementia which will in turn help to reduce and manage their own anxieties and those of the individual and the family of those being assessed.

Five skills for GPs have been identified that are needed to improve detection, recognition and management of dementia in primary care – “pattern recognition; deductive synthesis to reduce uncertainty; dialogue and disclosure; disability perspectives; and case management with shared care” (Iliffe et al 2006 p327).

The benefits and advantages of timely diagnosis and intervention described in the literature include:

• Excludes other causes of memory loss and confusion that may be reversible and enables treatment of these causes (however rare)
• Reduces uncertainty for the individual and their family about their problem/diagnosis – may come as a relief
• Enables them to come to terms with their diagnosis
• Enables access to counselling and other support
• Enables the individual and families to find out about and address issues such as prognosis and the disease course
• Access to medication and non-pharmacological treatment, help and support
• Enables future planning e.g. to organise support and avoid crises - enhancing quality of life through knowledge and anticipation of problems
• Provides the opportunity to interact with family and friends in meaningful ways
• Provides opportunities to make appropriate legal and financial arrangements
• Enables issues like work and mobility (e.g. driving) to be addressed
• Enables potentially risky activities to be addressed – driving, smoking, cooking
• Provides opportunity for life and advance care planning

For services and practitioners advantages identified included:

• Data collection for local workload and resource planning
• Greater leverage for local resources for relevant community services
• Increased clinical experience and expertise - locally and nationally, especially in primary care
• Increased opportunity for local and national research
• Opportunity for use of existing and to develop assistive technologies

Research acknowledges the need for and role of health promotion initiatives that educate and raise awareness of dementia and reduce stigma by identifying the signs and symptoms, the benefits of early diagnosis and intervention and remodelling dementia as a manageable condition. The recent TV adverts launched in the Humber and Yorkshire region in March 2011 as part of a £1.2m government campaign are an excellent example of this approach, but also
carers and local carers’ and other support groups are perhaps an untapped health promotion resource.

**Early Intervention**
The Department of Health impact assessment of the NDS (2009) suggested that early intervention can be cost effective and improve the quality of life for people with dementia and their families and the available evidence suggests that:

- Carer support and counselling at diagnosis can reduce care home placement by 28%
- Early provision of support at home can decrease institutionalisation by 22%
- Even in complex cases, active case management can reduce admissions to care homes by 6%

Pre-diagnosis counselling and information is important, especially regarding the potential outcomes of the test results - e.g. implications for driving. Post diagnosis counselling is considered critical, but great sensitivity is required. As with breaking any bad news, how the diagnosis is given can impact significantly upon how individuals and their families adapt and cope in the future.

**Specialist Dementia Services**
The NICE Guidance for Dementia (2007) recommends Memory Assessment Services be the single point of referral for all people with a possible diagnosis of dementia. These services should also identify people with MCI and offer these individuals follow-up to monitor cognitive decline and other signs of possible dementia in order to plan care at an early stage.

Memory assessment services should include a full range of assessment, diagnostic, and therapeutic services to accommodate the different needs of people with different types and severities (from mild to severe) of dementia and the needs of their carers and families.

The memory assessment service in Hull provides a single point of access for specialist assessment and triage for the early recognition of older people with memory problems, i.e. suspected dementia or mild cognitive impairment, and their families, by GPs and Primary Care Practitioners. Referrals are accepted by anyone and self-referrals are also accepted.

Early diagnosis and intervention are not always easy to ensure, therefore secondary prevention activities are also needed and should be aimed at reducing the impact of established dementia.

NICE (2010a) have defined a population benchmark rate for new referrals into a memory assessment service per year of 0.19%, or 190 referrals per 100,000 population.

In June 2009 the Office for National Statistics (ONS) estimated that 262,400 persons were present in Hull; the city’s population is projected to reach 317,900 by 2033.

NICE (2010a) suggest that

“For a standard primary care trust population of 250,000, the average number of people requiring referral to a memory assessment service would be 475 per year. For an average GP practice with a list size of 10,000, the average number of people requiring referral to a memory assessment service would be 19 per year”.

However, the guidance also very clearly states that these figures represent “a minimum expected rate of referral”, in recognition that “a large proportion of people who develop...”
dementia are currently likely to remain undiagnosed, or will not have their condition diagnosed until the disease has progressed” (NICE 2010a).

Using the NICE figures, it can be estimated for Hull that nearly 500 new referrals could be made to its memory assessment services per year, rising to over 600 per year by 2033.

YHIP’s Regional Review of Dementia for Hull (Brown 2009) showed 148 new referrals were made to Memory Assessment Services for the year April 2008 – March 2009 (30% of the average number of people requiring referral); between April 2009 and the review visit in November 2009, 105 new referrals had been received which, if referrals continued at the same rate for the rest of the year, would equate to approximately 180 new referrals (36%), a slight increase on the previous year.

It is also recognised that the time it takes to make a diagnosis can vary depending upon what scans or other investigations are needed and waiting lists. The average wait time from receipt of referral to first (face to face) contact with the Hull Memory Service was 12 weeks; the average waiting time from referral to CT/MRI scan for clarification of dementia diagnosis to scan date was 3 – 12 weeks (more usually 4 weeks). A 6-12 month period of monitoring may be required for those in the early stages of dementia, before a diagnosis can be made.

### Assistive technologies

There is potentially a significant role for new technologies in enhancing the lives of people with dementia and their carers and families. These technologies, which are improving all the time, can help individuals with dementia maintain some day to day independence (e.g. memory aids and prompts), can help to limit and controlling risks, so safeguarding the individual and providing some peace of mind and independence for carers and family (e.g. ‘smart’ home technologies, monitoring and tracking devices and telecare). Some technologies can be used to directly support psychological and emotional wellbeing, such as reminiscence aids (Nuffield Centre for Bioethics 2009). However, these technologies are often only really useful during the early stages of dementia and do not replace care: “it goes without saying that assistive technology can only be effective when combined with good care” (Alzheimer’s Society 2008).

### End of Life Care

End of life care decisions are also considered difficult, especially for carers and family when the views and wishes of the individual with dementia are not known. Research suggests that carers and families are helped by knowing the end of life views, wishes and preferences the individual held before losing capacity, together with “clear prognostic information, knowledge about future quality of life, and family support” (Livingston et al 2010 p8). This then suggests that end of life care views and preferences need to be addressed early in the disease trajectory.

The NICE End of Life Care for people with dementia commissioning guide (2010b p5) states: “People with dementia who are dying should have the same access to EOLC services as those without dementia. However, treatment decisions differ for people with dementia from other people approaching end of life in two ways. First, the decline in health is less predictable and more variable, making prognosis difficult. Second, the deterioration in communication skills prevents people with dementia from expressing their views and wishes later in the disease pathway”. 
Whilst there are still gaps and room for improvement in the local end of life care pathway for dementia (such as poor planning, lack of confidence and skills and poor bereavement support), these issues are beginning to be addressed.

There are some excellent local end of life care (EoLC) and advance care planning (ACP) practice examples using the advance care planning tool called ‘Living Well: Thinking and Planning for the End of Life’ (Helen Sanderson Associates 2010), developed from the national preferred priorities of care initiative. This tool has been used locally to enable those with dementia to communicate more effectively about their end of life care needs with family and professionals and to have these documented; “the decision making agreement took into account her ability to make decisions when she is feeling well and when she is unwell, clearly documenting what decisions she still wanted to make herself and which decisions she was happy for either her daughter or district nurse to make on her behalf” (Wigley and Meyerhoff p11 2010). This approach to EoLC planning and ACP has been shown to improve physical (pain and symptom management) and psychological care at the end of life. It also meets the aims of the personalisation agenda well both regarding person centeredness and also regarding improved interagency and partnership working and the benefits of this.
Project Methodology

The project was funded by a Department of Health award from their “Reaching out to Carers Innovation Fund”. The project was called “The Needs of Informal Carers of those living with Dementia”; the project commenced in January 2011.

There were 3 parts to the project:
1. Work undertaken by an appointed consultant
2. Work undertaken by HCHfH staff
3. National 1 day conference organised and hosted by HCHfH

The work undertaken by the external consultant resulted in a project report and presentation of findings at a Dementia Conference on 15th April 2011. This work consisted of:
- a non-exhaustive literature review
- a broad appraisal of current local services
- recorded interviews with carers of relatives with diagnosed dementia

The work undertaken by HCHfH consisted of:
- Representatives from HCHfH (e.g. Carers’ Support Scheme, Volunteer education and management and assistive technology support) initiating and attending meetings with a wide range of local providers of services for individuals and their carers with dementia.
- Representatives from HCHfH conducted an independent review of dementia awareness training packages and resources to support the education and training of their staff and volunteers.
- Organising and hosting a 1 day Dementia Conference held in Hull on 15th April 2011.

The Literature Review

The literature reviewed and reported upon the following topics:
- Current understanding of Dementia – types, causes, nature, incidence, prevalence and life expectancy
- Demographics nationally and locally of older people and individuals with dementia
- Carers of those with dementia
- Relevant health and social care policy and national agendas
- Local strategy and service reviews
- Service provision and workforce issues
- Timely diagnosis and intervention

Local Services

In addition to reviewing local health and social care strategy, policy and service review documents, meetings were also undertaken with representatives from the local Carers Centre, a local voluntary and community sector umbrella organisation, a local dementia care support group and the Hull Memory Clinic. Conversations were also held with the local Alzheimer’s Society, Age UK and the Goodwin Centre.

Recorded Interviews

It was acknowledged that the limitations of the project would impact upon the number and scope of interviews conducted. It was initially hoped to interview some individuals with the...
early stages of dementia as well as carers, but this was not achievable in the end and so a range of carers only were interviewed. It was also hoped to have a mix of focus groups and one to one interviews, in recognition that both approaches have merits and limitations and a mix of the two would best support the needs of the project. It was hoped to use established carers groups, e.g. within residential care settings, to facilitate the focus groups. However, establishing focus groups was not successful, and this was in part affected by the economic and political upheaval that social services in the city were undergoing at the time.

A combination or mixed sampling approach was adopted. Recruitment was directed by a combination of factors – convenience, typicality, information rich cases and range of variation. Ultimately those who took part were self-selecting. Potential participants were contacted in the first instance by HCHfH; recruitment was supported by a concise information sheet, face to face and telephone information and support and contact details for further discussion if needed.

Formal written consent was not sought; implied consent was agreed upon - i.e. attendance at interview or recorded verbal consent regarding telephone interviews. All interviewees were made aware that the interview was to be audio recorded and how the data and the recording would be used – intelligent verbatim transcription, summary data, anonymous quotes and recording destroyed after the end of the project. All interviewees were made aware that they could withdraw their consent or terminate the interview at any time; HCHfH were apprised of all dates, times and progress of all interviews. Telephone interviews were conducted in accordance with current UK legislation i.e. Regulation of Investigatory Powers Act (2000) and data held in accordance with the Data Protection Act (1998).

Semi structured interviews were conducted using a predetermined interview guide to loosely direct the discussion and roughly adhered to a "funnel structure" (Greenbaum 2000). The interview guide was developed collaboratively with the HCHfH project team and informed by relevant literature and asked the interviewee to tell their story in their own words outlining their journey so far. The transcriptions were provided using a predetermined template to allow for statement and code frame analysis.

The interview guide broadly covered the following:
- At the beginning - when/how did they realise something was wrong?
- How long was it before they sought help?
- How did they get a diagnosis?
- Did they have any previous experience of dementia?
- What was their daily life like – what was it like being a carer?
- What sort of crises had there been?
- What were considered the tipping points for residential care?
- What help did they get and from whom, was it what they wanted, was it helpful?
- What help did they think was missing?
- What did they feel their relationship was like with the ‘professionals’ – did they feel valued, listened to, have their opinion sought, did they feel part of the care team?
- How would they feel about having help from a volunteer?
- How did you feel about assistive technologies?
- What advice would they give to someone else?
- What would you say to someone who was just starting this journey?
- Is there anything else they would like to say?

Carer’s Interviews
A total 8 hours of interviews were analysed:
• 9 recorded interviews - 6 face to face, 3 via the telephone.
• 3 men whose wives were now in residential care (though very recently (within the last 4 months) for two of these)
• 4 women - one whose husband had been in residential care for 6½ years, the other 3 were caring for their spouse at home and one husband with dementia had a prior diagnosis in 2000 of Parkinson's disease.
• 2 daughters - one whose mother was the carer the other her father was the carer - both parents with dementia were being cared for at home.
• 7 of the individuals with dementia were diagnosed with late onset dementia (over age 65) two with early onset dementia (under age 65)
• The period of time since the dementia diagnosis ranged from 3 years to 9½ years
• The period of care at home for dementia ranged from 3 years to 8 years
Key Findings From Carer’s Interviews

NB Please note that throughout the following section the term ‘Carer’ is used to refer to informal carers i.e. family and friends providing care to the person with dementia.

‘Professional’ or ‘formal’ care or carers refers to care provided by an organisation e.g. domiciliary care service, social services, charity - and to the paid care workers or volunteers who deliver the care.

Wherever appropriate carers’ own words are used though anonymity is preserved.

Where did it all start?
The Carer could often pinpoint when things changed. This was usually after, in and around a period of significant change/doing things outside of the normal day to day routine:

- After a ‘traumatic event’ e.g. 2007 floods,
  - which required moving out of their home for a period of time and or living with the disruption of building work, ‘strangers’ in the house undertaking the remedial work and a break from normal routines
- During/after hospitalisation for something else
- During/after a holiday
  - this included anxiety or confusion at home preparing for the holiday e.g. packing
  - anxiety or feeling lost/overwhelmed at the airport
  - not being able to adjust to new surroundings whilst on holiday – waking up disorientated in a morning or becoming disorientated
- After retirement
- As a late stage complication of another disease e.g. advanced Parkinson’s disease.
- A sudden cognitive change after waking up from a ‘cat nap’ e.g. not recognising their spouse
- After the death of someone close

What changes did you notice?
The changes varied and were usually quite subtle at first. With hindsight many carers stated they could now see there had been signs before the ‘main event’- this was sometimes even years earlier, but they had not realised what they meant.

This is a cause of feelings of distress and guilt for some carers even now, many years after diagnosis. At the time they may have been impatient with the person, becoming annoyed and frustrated with their forgetfulness or awkwardness and giving verbal vent to these feelings with the individual. These feelings were also in some instances due to not recognising there was something wrong earlier and so not initiating any investigations or treatment which they feel may have had a detrimental effect - i.e. earlier intervention may have prevented the rate of decline, perhaps.
The early changes reported included:

- short term memory loss
- periods of looking/feeling lost (vacant)
- incidents of going completely blank
- getting lost in what were familiar surroundings
- no concept of time – ten minutes seemed like hours
- lack of confidence, tearfulness & anxiety (can be confused with or complicated by depression)
- communicating and socialising less with people
- seeming depressed and withdrawn
- poor personal hygiene
- mixing up medication and not remembering having already taken it and taking it again
- buying things not needed or lots of the same thing but keeping them unopened and unused
- unusual behaviour for them – becoming very vocal and swearing, for instance, or aggressive or argumentative
- not able to cope with unfamiliar surroundings – e.g. getting agitated and distressed when on holiday, or not knowing where they are
- not recognising familiar surroundings or their own home (and asking to go home)
- not understanding how things work (e.g. a stair lift), or how TV works
- cannot follow the story in a TV programme, or in a book or article though still able to read, and often don’t remember if they have seen or read something before.
- older memories can remain very clear and may even improve in clarity and detail.

‘And then medicines were mixed up and things like that and she said, “Oh I’m sorry I forget”, you know? Little things but looking back that could’ve been the start of it and you just don’t pick up on it, you say “You silly devil what you doing?” you know. But looking back I think it must’ve been just after her mother died when she started to get like that. So that’s eight years.’

Usually at this point close relatives are still recognised but younger relatives, e.g. grandchildren, may not be, or names are forgotten.

**Diagnosis**

Usually the person showing such changes was taken to the doctor (GP initially) or a GP brought in by their partner or another relative after, or as result of, one of the events described above. Seeking help or a diagnosis was not usually initiated by the person with dementia.

**Carers’ Suggestion**

Get a diagnosis as early as possible, go to see the GP as soon as you think there is something not quite right and do not be put off, insist on getting ‘dementia’ tests and keep pushing for a diagnosis. This will get you better care and support and help you keep the person at home longer – often getting a diagnosis is a relief for both the carer and the person with dementia.

“He found the diagnosis a relief – he said, ‘I thought I was going mad’. He calmed down a lot after that.”
Diagnosis is not always straightforward:

"In 2007 it was a very thin line between depression and dementia at that stage. And his reactions could’ve been slowed down because of the depression rather than dementia. So we spent six months treating him for depression."

A brain scan might show nothing – "They said it was the brain of an average 75-year old man...... Then he was really bad. And I didn’t know what to do, and I didn’t understand. Then he went for another brain scan and that came back clear too.”

"His dementia is as a result of high blood pressure that was poorly managed for many years. The GP was repeatedly told of his memory and behavioural difficulties. After 2 years we transferred to another GP who referred him to the memory clinic - I felt it was a relief to get a diagnosis.”

"We were sleeping in separate bedrooms and she was shouting me – I remember ten, eleven times one night. She was falling out of bed and I had problems getting her in ... back into bed, and in the end she went into hospital. This was the GP’s decision because I sent for him. I said, ‘Look, we’ve had such a terrible weekend’ and he said ‘Look. The way to get her assessed is to get in as an inpatient. If she goes as an outpatient there will be delays. Let’s get her in.’ "

**Carers’ Suggestion**

One route suggested by a carer to help one’s GP recognise and take symptoms seriously was to conduct your own ‘dementia test’ with the person with memory problems using one of the recognised tools and take the results of this together with the person with memory problems to a GP appointment.

**Carers acknowledged that it can be hard to accept the diagnosis, they can’t understand why it has happened or they need to find a reason for it.**

"Problems occur when the same GP doesn’t treat her and then that has a knock on effect because when a GP comes in and says whatever and it’s not consistent then my dad will say ‘this is a load of rubbish this. I mean she must have got the diagnosis wrong in the first place. I don’t think she’s got this blooming Alzheimer’s’."

"She was taken to A&E by ambulance and assessed there by a mental health doctor and given a diagnosis of Alzheimer’s (but I don’t know how they arrived at that diagnosis so quickly).”

"My daughter has kept reminding me - when I kept thinking my wife’s going to come home one day, and they’ll find out what’s really wrong with her one day, - that they won’t ... and that she won’t. She’s very down to earth about things like that.”

"I was unaware the dementia could be related to PD – I wish if someone had sat down and really talked to us in the very beginning as to how – the direction everything would go, we could have made different decisions.”
"But it was always viewed that it was, it was her nerves. And my dad to this day says it's because she was evacuated to Scarborough during the war and a bomb hit the house she was in. Have to find a reason for it, you know?"

"There wasn’t any history of it in the family they all lived to their 80-90’s OK, he is only 75.”

**Previous Experiences of Dementia**

Some of the carers interviewed said they didn’t know what to expect as the disease progressed but knew it could be very variable and so it could be difficult to be informed. Some knew very little about the disease, its causes and how it could progress, and some did not want to know. Others had made themselves aware of the disease and many had had previous experience of it – parents or parents in law or grandparents.

The nature of a carers’ previous experience of dementia, if any, did influence their expectations of the disease and their fears and concerns regarding diagnosis. Those with no direct experience of dementia were, they said, made aware of dementia though hearsay or the media.

Carers felt that the quality and nature of their previous experience and perceptions of dementia, be it negative or positive, had a profound impact on their current perceptions, expectations and fears and ultimately on their adaptation and coping.

Regarding previous experience of dementia the scope of this experience included their direct involvement in care, the nature of the symptoms encountered, how the symptoms were understood and managed by them or other family members, the impact of the disease on the individual but also on the wider family and where/how the person was cared for.

"My father had dementia – this experience makes my husband’s diagnosis devastating – it is the worst disease you can get.”

"I had my mother in law living with us….she was 93 when she died. So we had her for three years down here, and she was a joy to look after….she was lovely to look after, all she wanted to do was sing, and look after these imaginary children that sat on top of her wardrobe.”

Sometimes it is only with hindsight that they realise they have perhaps had some experience of dementia before –

"I have but I didn’t realise at the time, my mum. ...I realise now some of the things she said, she had it.”

One of the daughters commented her parent’s generation did not see mental illness and dementia as we do today, she said her father had commented it was “oh they’re nuts put them in an asylum” and so he believed this was still people’s attitude to dementia as being mad or demented, which deterred him from seeking or accepting outside ‘official’ help in fear of having his wife taken away from him. She also got the impression that many working class people of this generation did not see mental illness as an illness – it was a curse or the result of having done something wrong and this perceived stigma and shame would deter these people from seeking help.
What services are available?
There was commonly a very poor awareness of what help and services are available both early on and also later on as the disease advances.

Carers commented that it was a constant battle to find out what was available and then to be able to access them. Carers often felt let down and frustrated by services.

Whilst it is recognised that a variety of services are needed and that different services suit different needs, there is also some concern expressed that there is so much variation between centres, services and areas (post code lottery) and between what is available or what people know is available. Issues of quality were also raised - what is best practice, what common standards should be applied that will also support variety?

Carers Suggestion
Access whatever support you can - negotiate it and keep yourself at the centre of the care team – make them listen to you and involve you.

Communication and Continuity
They commented upon the poor communication between services and service users and poor coordination and communication between services. The role of health, social services and the third sector in providing services also needed to be clarified. A particular issue was regarding poor continuity of care within a service and a lack of reliability – a ‘buck passing’ attitude was often encountered. Carers had issues in the main with the management and coordination of services, e.g. care coordinators, and with what they actually provided.

“We had a good relationship with the carers; it was the management that was poor.”

“We want care and services suggested that can actually be provided – to be realistic and that providers work with the family carers to ensure they understand what is happening, and provide them with reassurance and support.”

“That’s what I have found all along. Frustration about the fact that different services weren’t communicating well with each other. That was a big issue more than once.”

“All these uncertainties and nobody knew ... No one would take responsibility and coordinate it. Yes. It was the communication that really irritated a lot.”

“Social Services became involved and they decided, listening to what the carer had said, and how aggressive she was that maybe respite care was something that my Dad needed. But the whole picture wasn’t looked at...... my mum, regardless of all this, my mum does know certain things are going on. You know, she is aware that somebody’s taking her to the toilet and helping her down with her pants and she doesn’t like that intrusion of her dignity and that’s when she’ll hit people”.

“Carers would come in the evening to put her to bed but this could be at any time from 5.30 pm onwards – but didn’t know when to expect them until they arrived (timings erratic). Again often she would not go to bed and so I was left to do this on my own.”
"I got a couple of hours on a Tuesday morning to go into school and read with the little children and help them read, you know? It was just to sit with my wife, just sit, and they didn’t do any housework because I’d do all that, you know, and she just sat with her and spoke to her. But the agency that took over couldn’t do mornings so I had to go to the school in the afternoon, and it was getting real awkward They was coming at half one, quarter to two, and that was no good for me. I started not to go. I’d go and do shopping or I’d do something else. And I felt a bit cheated with it like, you know?"

"….then she went in to the care home - they [carers] still keep coming out even though I have cancelled it. I mean its lack of information, they’re not passing information on.”

Carers’ Suggestion

Poor record keeping was also reported and carer held record/notes were suggested as a solution to this.

"Yes that seems to be a real anomaly to me. People seem to spend more and more time record keeping, but the record keeping isn’t consistent or even … And it’s isolated … pockets of record keeping”.

Carers rarely had issues with the individuals who came to provide care, they often had good relationships with them but felt some were better educated, aware and familiar with dementia than others and some were more caring than others. Some carers felt it did matter to the person with dementia that different professionals came each time, others didn’t think it made any difference – the stage of the individual’s dementia may be a factor here. But lack of professional continuity could also be an issue for the carers.

"Yes it did. [matter that the people were different each time] Some were … some were easier to relate to than others, etc., and things like that. Yes. And it mattered to my wife Yes. Some were rough in handling her she said and things like that. Some were not good timekeepers and things like that. Yes.”

"Problems occur when the same GP doesn’t treat her”

"But there wasn’t one face, the same. No consistency. It was whoever was there, get in there like, you know. Well when somebody’s got dementia, they’ve begun to recognise a face and they know the voice and everything and they should have this, you know, same person going all the time."

"I mean to have some consistency and some continuity would have helped her a lot more, saying ‘Well I’m alright. I feel right. That’s smashing’……she can’t have felt safe if she’s getting a different face because her mind would be going ‘Who’s this? What are they doing?’"

“I have had that many people”

"Consistency with carers needed especially for the person with dementia – we had a good relationship with the carers it was the management that was poor.”
Continuity between day services and out of hours care need to be improved.

"And the worst one was that if we had to bring the doctor in at night, as we did several times, they seemed to be completely lost as to what was happening."

A need was also identified for more frequent reviews as the situation can change quite rapidly.

"Again all of a sudden the Social Services haven’t really been in touch since October. [They] Rang me to say…they would come down and interview me. And ask me what I would like…And I still (it is now April) haven’t heard from Social Services”.

"All they’ve done is put a bar outside so we can come up two steps into the kitchen and all they seem to think that we would need."

Having to constantly tackle service delivery issues impacted significantly upon carers’ stress and their own health, including accessing health care for themselves, e.g. attending doctor’s appointments, and quality of life. This also had, they felt, direct consequences on the care, safety, health and quality of life for the individual with dementia they were caring for. This can be a major contributory factor to carer burnout and a tipping point for seeking residential care placement.

**Variation and Quality**
There was also some concern expressed that there is so much variation between centres, services and areas and between what is available or what people know is available. Carers felt it was “a post code lottery”.

Issues of quality were also raised - what is best practice, what common standards should be applied that will also support variety?

**Expert Carers**
There is a wealth of expertise in the carers and wider family members that can help others – and though carers commented that professionals do not dismiss this, as they might have done in the past, they felt they do not embrace it as warmly and unconditionally as perhaps they might. Carers felt their experience and expertise could be shared with other carers and with professionals that would provide support and education but that would also help to promote social integration and reduce stigma, e.g. working with schools.

There is a suggestion that professionals need to be less controlling or paternalistic regarding the help and insight that carers can offer, to be more accepting and be less ‘medicalising’. Carers also found that communication between statutory and voluntary sector can be inhibited and barriers exist. There is also some protectionism and paternalism demonstrated by statutory services towards some carers’ groups and voluntary provisions

“Well to my mind there’s a lot of politics that get in the way. I find it oppressive”.

Different forms of professional and peer support suit different people and this became clear in these interviews when hearing of the range of informal and formal support that carers access and appreciate. Much of this is available locally, but it is not perhaps as well advertised or
signposted to as it might be. Whilst carers do appreciate the advice and support from professionals they equally value peer support and sometimes value this more.

Carers gain great strength from the experiences of their peers and from setting up their own support ‘groups’ or discovering individual ways to gain support; however, they would also appreciate some support and facilitation of this process, e.g. signposting.

All the carers interviewed also greatly appreciated being involved in this project and were pleased to know that their experiences and insight might be of help to others now and in the future. Some had been involved in other research activities, which included reminiscence work together with the person they care for, and they also found this of great value.

However, what the carers said they particularly valued from this project was being able to tell their story in their way - not just about their caring role but about their relationship with the person they care for and their wider family.

‘Professional’ support included:
- Friends of the Hull memory clinic - fundraising/support group
- Activities accessed through the carers centre and Hull memory clinic
- Individual relationship counselling, e.g. Relate
- Support provided by HCHfH services

‘Informal’ support included:
- Memory loss support group for carers and the person with dementia
- Care home based self-help/support systems and support groups set up by carers in care homes
- Time with family and friends

"Yes, and the other thing is that the therapist said to me, 'Look if you need to come back......because it's interesting after three times six weeks, well it became monthly, you think that's it, that's all that can be done; but to be told that there is still support there and help there if you feel you have not got through it as well as you had hoped to, is very reassuring.'"

There are also organisations more far afield that can provide help and support, however, some of these get mixed reviews - the positive reviews tend to come from the carers and the less positive reviews from professional organisations. For example SPECAL are an organisation that advocate a particular approach regarding communication with people with dementia that does not use direct questions, and they run courses for carers of those with dementia (www.specal.co.uk). Whilst this report is not recommending this approach it does acknowledge that for some carers it has proved very helpful. The Alzheimer’s Society do not support the SPECAL approach:

"The Society has serious misgivings about the SPECAL approach because it takes away choice and control from people with dementia. The SPECAL approach has some elements that do reflect best practice in personalised care. One of the reasons why SPECAL has been criticised heavily in the dementia care field is because it suggests a blanket approach to deception of people with dementia”

However, one of the carers interviewed for this project stated:
"I spent a day there [SPECAL] and it was a very important day......And their emphasis was very much on forget the intellectual side of the loved one, it’s the emotional side, the feelings side, to encourage and to get familiar with, and the positive feelings to be brought up when you are talking about the past. That was it. And to try and treat......try and understand what was going on in that person’s mind really. The thing I learned from SPECAL, which they stressed that day a lot and got us to think about it, was now that we were the carer or on our own, was to really focus on our own needs. You know to think about......and the argument is there isn’t it; unless you look after yourself well, you’re not going to be as good a carer or a visitor as you would have been.”

This perhaps highlights some of the differences between carers’ and professionals’ opinions and how at times carers can feel ‘patronized’. Ultimately carers’ choices and expertise do need to be respected and support provided to ensure any choices are informed choices.

It is recognised that safety is a concern but there is also a balance to be made between risk taking and safety that can improve person centred care.

“Models of risk in dementia care are poorly developed. At present, the risks faced by people with dementia and their families are most often defined by services and focus on safety and security. As a result, service provision is not fully negotiated with the person with dementia and is inclined to be unduly protective. However, this approach to risk does not always recognise the experiences, strengths and wishes of people with dementia themselves” (Gibb et al (2010), Clarke et al 2010a, 2010b). Nor does it recognise the experiences, strengths and wishes of their carers.

Therefore a risk enablement, or positive risk management, approach is recommended rather than the paternalistic or risk adverse approach more often adopted in health and social care.

“One of the biggest barriers to enabling people with dementia to have more control over their lives is an overly cautious approach to risk. ‘Safety first’ approaches are disempowering for people with dementia (Clarke et al., 2009; Nuffield Council on Bioethics, 2009)” (DH 2010 p6).

I would also suggest that a safety first approach applied to carers of those with dementia is equally disempowering.

What do you need?
A large part of carers’ responses related to the help, support and services they felt they needed and wanted.

To feel confident about the formal care being provided, and to know who to contact regarding this care provision.
Carers said they needed to know that those involved in the formal care understand dementia and the problems that go with it and that their intervention and care is appropriate and is negotiated with the carers and the whole picture is looked at.

Regular support and review was identified as needed and carers and the wider family needed to know who to contact if there is an issue or if something changed.
Long distance carers/wider family have needs too:

"I would appreciate personally, myself being a long-distance carer, I would appreciate somebody that I could talk to in an off the record......I’m looking at these homes and everything. I don’t know about the funding, where the funding comes from, what kind of funding do we get. To talk to Social Services there’s always a hidden agenda, you know, and I would like some impartial person who was the font of all knowledge to be able to ask my questions to."

Volunteers
Great – but they need to know about dementia, be happy to actively engage and communicate with the person with dementia and we also need to know they are vetted, supervised, insured and educated.

"[Hull Churches] stepped in and they really did give me a break that I really needed, yes. Every Tuesday. All I did was go swimming and most days I just went swimming. It really was a lifeline, you know, your organisation provided for me."

"My dad’s very stubborn. I don’t think he wouldn’t want people going in doing things like that (washing, cleaning, shopping). But if somebody said to him, ‘Come on, we’ve got a car here. We’ll take you for a ride’ or ‘We’ll take you and your wife to such and such a place’... you know Brid for an ice cream. I’m sure he would he enjoy that."

"They have been terrific - I have someone come every week for 3 hours so I can attend appointments or just to have a bit of time away from the house. Referred originally by district nurse – Hull Churches have helped whenever they can, I am very grateful. I also need a bit of time for shopping and so on – but I don’t want to take from other people."

"Help with the garden, help with the ironing etc. – just general practical domestic things especially as I have to give him more and more care."

To have our views listened to
Carers said they wanted to be considered as an equal partner in the care team but that this was not always the case.

Carers wanted stimulation for their loved one not just passive care – and they felt it should also be recognised that not everyone with dementia wants to be with other people with dementia.

Interventions - e.g. reminiscence work - needed to be appropriate and tailored to the individual/age group, especially those with early onset dementia who may only be in their fifties/sixties.

"She likes Abba and she’ll get up and dance to Abba if she’s in the mood and of course all the old songs, the greatest hits and everything. So she did like that."

Carers want to be able to do things with their loved one together, not just respite - some of the ordinary things like shopping, cleaning and gardening but also some more recreational activities that give them quality time as a couple, and may need support to do this. This wish to do things together continues after the person has been placed in a care home; for example, although his wife is now in a care home her husband books a taxi to take her out.
"I take her to Choir practice – we used to both take part. She can’t sing now but people know her there and I get to sing and we get to meet people – most times it works well."

Carers also needed things for themselves in their own right – respite, support time with friends, join a carers group - but equally not everyone wants time to themselves, and ‘traditional’ inpatient respite doesn’t always work.

**Informal support**
Carers appreciate informal support – good friends and family, even if of a similar age (e.g. siblings), and adult children - but the form of this support needs to be negotiated not assumed.

"One of the best things that has happened to me as a result of her being in the care home is that I’ve met up with people who are going through and have been through something similar to me. We’ve set up a little support group actually."

There is a cost (financial and emotional) to providing support and carers are very aware and concerned about this; they don’t want to be a burden to their family and friends. It is often felt that looking after the person with dementia is their responsibility because it is their partner and not the responsibility in the same way for the wider family. However, they can still be disappointed by lack of support from the wider family sometimes. It was acknowledged that this was sometimes due to poor communication between family members; expectations were not disclosed and assumptions were made. They also acknowledged that some family members did not get involved as they might because they had not come to terms with the diagnosis and did not know how to handle their emotions or how to relate with the person with dementia any more.

However, other family members often expect their siblings to take equal responsibility in providing help and support which can lead to resentment and family disharmony. In Hull there is still an emphasis on effective carers being women and there was some greater level of acceptability or resignation demonstrated, to an extent, if a male relative opts out of caring compared to a female opting out.

A place for ‘Befriending’, from volunteers for example, was identified.

**A say in how services are developed.**
Carers said that they did not mind paying for services (if they can) - e.g. day care - but regardless of whether they do or can pay or not they wanted the right sort of services and that the current services did not always match their needs. This suggests greater user involvement is needed in the planning, design and development of services.

Carers stated that winter time, especially with bad weather, is a particularly difficult time for them and the person they are caring for as their mobility and access to services they usually rely upon is often limited. They commented none of the services take a proactive approach to contacting them at this time and no alternative approaches to support or help were provided.

"I take him out as much as I can but while it was icy, I could have managed to a certain extent but I daren’t go out for fear if I fell and hurt myself, who’d look after him?"

"What I did want for … was for him to have some stimulation especially this winter. I mean neither of us could get [out] a great deal. I don’t think [he] went out for ten weeks because he’s unsure on his legs, you know?"
Some reassurance that the services they rely upon will continue
Local government upheaval and funding cuts have been a great concern to carers. Big changes in funding, service cuts and changes in how services are provided causes great distress to carers and compounds issues regarding continuity. This sort of upheaval also creates a lack of trust between carers and service providers; carers did not feel they were informed sufficiently, nor did they think their views and opinions, especially regarding the impact of these changes on the person they were caring for, were listened to or considered important.

Carers at one care home that was under threat were very wary of taking part in this project because they felt the information may be used against the home and help to ensure its closure. The significance of such changes to the individual with dementia and to the carers, they felt, were not considered well enough. Carers were worried that changes such as a change to the location of care would affect the quality of life and wellbeing of the individual with dementia - a new location and different staff might precipitate a decline in their health. A change in location could impact upon the time and cost of travelling for carers, which would have a significant impact upon their wellbeing and coping. If the residents from a care home were split up and distributed between other care homes this would impact significantly upon the informal support carers gained from each other. Carers also acknowledged that such uncertainty would impact upon staff morale and ultimately on the care they provided.

"I seem to be in the middle of a turmoil at the moment, what with all the cuts that’s coming along and things like that. They wouldn’t take him because they think they’re closing with the cuts and all that so. But the cuts also affect how they feel about the work, you know? Because if they’re worried about their jobs they’re not going to be giving 100% are they on some days. ...........My two friends and my daughter and her husband, they just absolutely hate going to work, you know?"

"And of course the cutbacks don’t help because at the moment we haven’t got a care co-ordinator, so to talk about, we haven’t had a care co-ordinator for two or three months now, and we were supposed to be getting another one assigned to my mum and that hasn’t happened and I think everybody’s just waiting for what the budgetary situation is. So we haven’t anybody to contact."

Help to consider the future
Carers wanted to keep the person they were caring for at home for as long as possible. Carers disclosed this was for a range of reasons that included feeling they should and not wanted to be on their own, but the key one was about their relationship "we’ve been married for over 40 years” "We’ve been together for 50 years” and that this was their home – "I mean we have lived in this house forty years. We are both attached to it. The children spent most of their childhood here, etc. We love the garden......”

Though caregivers may want to keep their loved at home, the needs associated to advanced illness, physical safety and the demands and stamina required to provide 24hour hour care need to be carefully considered and will require considerable support from others. This may be the prompt or ‘tipping point’ for placement in a care home (Wayne 2009).

"Look......we’re not going to put you in a home. That will be the very, very last resort."

"If physically I couldn’t do it – if I have got my health and strength I would prefer to look after him at home – I will need more and more help as he deteriorates but I want that
help here rather than he goes into a nursing home - I will avoid it as long as it is absolutely possible - it would only be a very extreme to put him in residential care but may need respite more often.”

Key problems for carers as the disease progresses are sleep deprivation, coping with their wandering, aggression or falls (e.g. out of bed).

**Carers’ Suggestion**

Help overnight would be good.

**Help to recognise they are not coping**

Carers also say that at some point they need a prompt to help them recognise when they are not coping. Some do have fears around safety sometimes – for them and for the person with dementia (safeguarding).

“Recognise when you can’t do the 24/7 caring anymore even with help and get them into residential care – think about what would happen to them if something happened to you?”

Because the carers’ intention is to keep the person at home, they have not always thought about where the person they are caring for would go if residential care was needed or what might precipitate this move - e.g. a crisis. Nor have they thought about who could take over the care if they become incapacitated in some way - advance care plans are not usually in place.

**Carers said they avoid thinking of residential care and end of life care because of:**

- Fears around the person being ‘taken away’ from them – of losing control over their care
- Feelings around it being their duty/responsibility and they would feel they were breaking their wedding vows – “they are your responsibility”
- Fear of losing the relationship - they have been married and living together for 50 or 60 years and probably don’t have much time left but what is left, regardless of quality, they want together.
- Fear of loneliness
- Fear of having to cope with the loss (grief and loss- pre bereavement) – having to acknowledge end of life issues – the hope that the person will come back to them even briefly (though they know this is unrealistic) lingers.

**Help to find a care home**

People find it hard to know where/how to start looking for a care home and need help to consider the impact care home placement may have on everyone – themselves and the person with dementia.

“You know everybody copes with it differently but that’s fine, we can all bury our head in the sand but we’ve got to be realistic about it as well and things have got to be done before crisis. I want to have things in my mind before crisis point arises because then sometimes in crisis point you make wrong the decision.”
"This is my problem at the moment. Because as I say I've been on the internet and looking but trying to find time, you know to have a long list for me, is not worth it. It's too difficult. I need a shortlist."

"So I think to keep people at home longer which is the best thing and in a way it's the best thing for the carer as well because once they've gone into the home it doesn't stop there. Often it's even worse because you've got a journey to get there. That sort of stress, and then if you really can't get there one day you feel so guilty because you've not gone and it's a whole [day]. Yes it solves one set of anxieties but then brings in another load really - it's a whole different set of anxieties and worries but they do still need support then."

**Help to cope with the guilt**
The decision for care home placement "broke my heart."

Carers often have feelings of guilt after care home placement - though feelings do, of course, vary between individuals common issues are:

- Are they doing the right thing?
- Is it better for their loved one?
- Are they being selfish?
- Are they a failure? (Is it really that bad)
- Will their loved one deteriorate or die quicker as a result (in effect are they sentencing them to death) – here the quality of the care home and care is a very big issue.

"The guilt's quite... I mean I remember granddad went into the home that there was actually no other way we can do it, and we just. I mean I felt dreadful. It was a horrible, horrible thing to have do and you do feel guilty and you feel bad and....."

Even when carers truly believe it is the best thing and in their loved one's best interests, and they acknowledge they have more better quality time with their loved one now, the feelings of guilt persist and it isn't always 'plain sailing':

"BUT I feel incredibly guilty and I feel a failure they are your responsibility – the best scenario would be to keep them at home until they died – however unrealistic this may be. Therefore you leave the residential care decision as long as possible – even after years I still feel guilty but appreciate the benefits more too I suppose."

"That's another thing, you start to talk like "them" [as in them and us], don't you? I know she's in there now and somebody said this to me right at the beginning and I'm just beginning to really believe it now, that every hour I spend with her it's quality time, you know? I'm not being tortured."

"I had the operation, I came back and went up to see her [in the care home] after a few days in hospital, and one of the first things she said to me was 'Now you've got a new knee I'll be able to come home again.' So she had got it in her head that once I was fitter ... And we had this discussion about what it would mean. It was quite a rational discussion about what it would involve, extra care, people coming in, and so on ... and she has not mentioned it again, so .... That was horrible. I failed to see that she would think of it like that."

Often the decision for care home placement comes out of a crisis and a period of respite care.
"She was there 6 to 8 weeks until they found a place for her to go into residential care. Initially as...not as a full time resident, but for respite care. That’s what it was. But that respite care changed into permanent or long term. Now it’s permanent."

"And she’s in there permanent now. And I haven’t got the heart to tell her. I couldn’t tell her”. Do you need to? “No I don’t think I do. I don’t think I need to tell her. It’s a hell of a thing.”

Help to cope with loneliness after residential care is secured and to be involved in care if we can/want to

The carers interviewed did still consider themselves carers even if the person they were caring for was now in residential care. Some carers wanted to continue to be almost as involved in their loved one’s care once they are in residential care as they had been before at home. Others wanted to not be judged if they can’t or don’t feel they can do this.

"I go every day, yeah”.....So would that make any difference if it comes to a point where she doesn’t recognise you?” No because I’d still know she’s there. You always have that little thing in your mind about if I don’t go, she’ll be ‘going where is he?’ And then you’d never know that because you haven’t been there and when you go in constantly all the time, there might always be that little breakthrough, ‘Oh he’s here’, you know?”

Some carers acknowledged that though it was difficult caring for their loved one at home being that busy all the time meant they did not feel lonely in the way they did after residential care was secured. They also found that because of having been a full time carer for so long other activities and hobbies they might have had in the past had lapsed and it was now difficult to pick these up again or think about what they would like to do for themselves in their copious free time. Some carers acknowledged that this loneliness and loss of purpose did influence to some extent how frequently they visited the care home and how long they stayed.

"Empty days, yes. Lots of empty days. So the house.....I still find it difficult to tell people......to talk about my house and my home, instead of using the word ‘our’...... I mean it’s just a lot of big adjustments to my life as well as living without her”.

"Workload’s disappeared completely and I tell you what’s difficult really, cooking for one. It’s still early days. I mean the dog’s never been for so many walks. I was walking him at seven o’clock this morning. And the house is, well it’s empty isn’t it?”

But it isn’t all bad:

"And another thing I get to go and watch my grandson playing rugby now. Which I couldn’t do before and I really enjoy that. You know, it’s nice. "

Help to plan ahead for end of life care and death

Preferences regarding care at end of life, death and care after death, e.g. funeral arrangements are not routinely being discussed; formal advance care plans are not routinely being negotiated. But this can be done as part of normal care planning and ties in with reminiscence work too – a missed opportunity perhaps?

"Well we know it’s cremation. We’re not religious though it’s going to be humanist
It doesn’t have to be a traumatic thing. Yeah, but it’s a bit thinking outside the box a little bit isn’t it really to deal with it. Bit like the life story books? I mean, it’s one of those. It’s a really difficult one…..”

“At a friend’s funeral…..there were all these poems and things that she’d chosen herself, and it was actually just like listening to her speak because it was just, ‘Oh yeah that’s really…..’ You know, ‘that’s really the type of thing she’d say’ ”

Help with wills and power of attorney

Carers’ Suggestion

Get bank accounts, savings, wills and power of attorney sorted out now before there are any problems and while you can – need information, education and advice regarding pensions, ISAs, joint house owing etc.

Very few people seem to have these in place before any problems occur – even older people - some action may be taken to sort things out once memory problems occur or a diagnosis given – often it is too late to do everything they would like and too costly now to take it further.

There also seems to be poor understanding about power of attorney, i.e. that there are care and financial elements now, and why a will is needed. Therefore some education around these issues together with mental capacity, advance directives and issues regarding resuscitation and advance care planning are needed.

“Well I won’t say power of attorney. I had to fill in a tax form for him every year and I’d already got that changed and yes his pension I’ve got the power of attorney.”

“I have his power of attorney and talked to the solicitors recently – no we didn’t have all this in place as we should have done – we didn’t have the right information and I looked on Parkinson’s like a lot people, as a physical thing I didn’t realise all the issues…..I didn’t expect any of this.”

We want (and need) Education and Support

- About the disease
- About what it is like for the person with dementia
- About services and benefits
- About mental capacity and power of attorney, wills, advance care planning, advance directives and resuscitation
- About what might help me
- About making difficult choices and decisions and negotiating with the rest of the family
- About how to communicate effectively with the person with dementia
- To be involved in educating others – form carers and professionals
- What are the sort of things that would really help keep people at home?
- About new skills
- About assistive technologies
“Looking after the carer. And the carer is the wider carer group. Education, I would say is a big thing too. About the disease and about how to cope with the disease, for the rest of the family too.”

“New skills - Cooking, cleaning, shopping, personal care, financial responsibilities, how to communicate with someone with dementia (e.g. coping with repetition), how to cope with aggression, making decisions (negotiating with the rest of the family)”. 

Assistive Technologies
All the carers were very open to ideas to have assistive technology for both health and safety (H&S) reasons and for psychological support. Assistive technologies were accepted as useful in both care homes and in the person’s own home.

Though some carers had some awareness of the technologies, the full range and potential of such technologies is not fully understood and so some education regarding this would be good. Education and support are also needed to accompany decisions regarding technology and to support installations; regular reviews will also be needed as things can change quite rapidly.

It was suggested that regarding H&S once the disease progresses use of night time alarms, pressure pads and red buttons for the individual may not practical – but alternatives to more standard installations may be available and this could be discussed with the individual. However, this also suggests that this technology may have a particularly useful role earlier in the disease trajectory.

“Well he’s always up during the night. He’s up about five or six times during the night. They would be going off all the time”.

“So she, the pressure mat is one of those ones that sets off an alarm off. Yes. Well they all have a beeper on them and it tells them what room it is, and they also put a pressure mat beside all the beds as well, once they get out of bed they know they’re up, you know. And did you have anything like that at home? No, not a thing, no. You just get tuned in don’t you? Something like that would have been very useful”

“Life line very useful – use it on several occasions. Probe have fitted CO2, temp and Fire alarm all connected to life line – it is fantastic - all tested once a month”

So you can have pictures and then you can have the voice talking about them as well - to help the psychological side of things. "I’d love to use that for memory"
What did carers’ appreciate most?

- Carers appreciated being afforded time for them to tell their story, talk over their memories and their lives too - not just their story of dementia but their life story and the story of their relationship with the person with dementia, and other experiences of dementia and their hopes and fears for the future.
- Some wanted to talk about their role as carers and some stated they’d had or wanted to have counselling about the changes in their relationship.
- A need was also identified for carers to be screened and treated for depression too, especially when there was a history of anxiety, depression or mental illness or psychological issues in the past.
- All the carers appreciated being involved in the project and were pleased that their views, opinions and experiences were valued in this way.
Conclusions and Recommendations

The overall aim of this project for Hull Churches Home from Hospital was to identify and assess the help and support needs of carers in Hull caring for individuals living with dementia, in order to ensure that their Carers’ Support Services would meet real needs.

The part of the project reported here was undertaken by an external consultant and consisted of a non-exhaustive literature review, a broad assessment of local dementia services and recorded interviews with a selection of carers. In addition to this work the carers support scheme staff undertook to meet with a wide range of dementia services and associated initiatives across health care, social care and the voluntary sector in Hull to provide a more detailed scoping and mapping of current provision and to network with local providers. They also made enquiries to evaluate current trends, initiatives and best practice regarding dementia care education, to inform their dementia education programme for volunteers and staff. They also investigated further the range and scope of assistive technologies pertinent to dementia care. These findings are reported elsewhere.

Reviewing the literature and local context

Dementia is considered a common disease most often associated to older age and is slightly more common in men than women; current predictions suggest the number of people with the disease will double over the next 30 years. In recent public polls dementia is now cited as being more feared than cancer. Dementia is life shortening and associated with complex needs and high levels of dependency; the median life expectancy is about 8 years from onset of disease.

50% of all cases of dementia have a vascular component; atherosclerosis is a risk factor for vascular dementia and risk factors for atherosclerosis are associated to deprivation. Hull City Council is the 11th most deprived local authority (out of 354) in England, and is in the bottom 10 - 20% deprived nationally in most domains. Deprivation is also associated to higher incidence in younger age groups (age 60-79 years) (Raite et al 2010).

In Hull it is estimated that 2,633 people have some form of dementia; this figure is predicted to rise by a further 29% by 2025. About 900 of this total figure currently have a dementia diagnosis, i.e. are on GP registers with a dementia diagnosis. The remaining 1700 (66%) are living with the condition but don’t know about it, perhaps because it is a mild form, or they have not sought a diagnosis. Many residents in care homes have some form of dementia and estimates vary between 50% in residential care to 80% in nursing homes. In 2008 in Hull it was estimated that 919 individuals with late onset dementia were living in some form of care home; this is predicted to rise by 35% by 2025.

Local dementia services are typical of dementia services found in much of the UK. They cut across mental health and older people services alongside primary care, social care, acute care, care homes, and the independent, charity and voluntary sectors. Funding sources vary, there is no overarching coordination of services, and staff are generally ill equipped to address behavioural changes in general settings and physical issues in mental health settings. Whilst current services are insufficient to address the existing issues there are pockets of innovative developments such as the Hull Memory Clinic and their stepped approach to care, and a local dementia strategy has been implemented which has led to some service development; some new roles and services have been implemented such as dementia leads, nurse specialists (e.g.
Admiral Nurses) and new services are planned - e.g. outreach services from the Alderson Resource Centre.

Advance care planning and end of life care planning are both under-developed in dementia care. End of life care decisions are difficult but carers and families of those living with dementia are helped by knowing the end of life views, wishes and preferences of the individual held before losing capacity, together with “clear prognostic information, knowledge about future quality of life, and family support” (Livingston et al 2010 p8). Advance care and end of life care views and preferences need to be addressed early in the disease trajectory. Whilst locally there are gaps and room for improvement - e.g. poor planning, lack of confidence and skills and poor bereavement support - these issues are beginning to be addressed. There are some excellent local end of life care (EoLC) and advance care planning (ACP) practice examples using the advance care planning tool called ‘Living Well: Thinking and Planning for the End of Life’ (Helen Sanderson Associates 2010), developed from the national preferred priorities of care initiative.

Whilst the benefits of early diagnosis and intervention in dementia are well documented and are policy directives nationally and locally, this is not always easily achieved. Making a diagnosis of dementia is often difficult, particularly in the early stages. Locally GPs are commonly the first point of contact regarding dementia assessment and diagnosis; the person with dementia rarely presents themselves, presentation is usually driven by the carer. Research reveals that there is poor detection and moderate recognition of dementia by GPs, partly associated to lack of continuity of care and poor skills but also that they may want to avoid the emotional distress associated to making such a diagnosis for them as well as for their patient and their family. GPs also felt that existing assessment tools were too long for everyday use and were not diagnostic. GPs stated they needed both education and support.

Poor recognition of memory problems by carers and the person with memory problems can also lead to late presentation, but there are other more complex issues that may also affect presentation. A shift is required in the carers’ attitude to the person they are caring for from seeing them ”as an autonomous adult to being their spokesperson” (Livingstone et al 2010 p7); this may take some time as it is a difficult adjustment to make. Carers also recognised the ‘risks’ or ‘hazards’, i.e. the impact that a positive dementia diagnosis would make on their lives, which may also delay presentation, though perhaps unconsciously. Research and policy acknowledges the need for and role of health promotion initiatives that educate and raise awareness of dementia and reduce stigma by identifying the signs and symptoms of dementia, the benefits of early diagnosis and intervention and remodelling dementia as a manageable condition. The recent TV adverts launched in the Humber and Yorkshire region in March 2011 as part of a £1.2m government campaign are an excellent example of this approach; locally carers and carers’ and other support groups are perhaps an untapped health promotion resource.

The NICE Guidance for Dementia (2007) recommends Memory Assessment Services be the single point of referral for all people with a possible diagnosis of dementia and that these services are pivotal in establishing early diagnosis and intervention. NICE (2010a) have defined a population benchmark rate for new referrals into a memory assessment service per year of 0.19%, or 190 referrals per 100,000 population – this is a minimum expected rate of referral. Using these figures, it can be estimated for Hull that nearly 500 new referrals could be made to its memory assessment services per year, rising to over 600 per year by 2033. Between April 2009 and March 2009 148 new referrals were made; to the Hull Memory Service and for 2009/2010 approximately 180 referrals were made, this is just 38% of the new referrals that could be expected to be made. The average wait time from receipt of referral to first (face to
contact was 12 weeks; the average waiting time from referral to CT/MRI scan for clarification of dementia diagnosis to scan date was 3–12 weeks (more usually 4 weeks). A 6–12 month period of monitoring may be required for those in the early stages of dementia, before a diagnosis can be made. This referral rate confirms perhaps that there is poor recognition of dementia in primary care and improved recognition may lead to increased referrals. However, the waiting times also suggest that service capacity is limited and that current services could not cope with any significant increase in referrals. There may be as much as a 60% shortfall in local memory assessment and dementia service provision which could impact significantly upon the early diagnosis and intervention of dementia in Hull.

Carers have a right to an assessment of their needs; but evidence suggests that a half to two-thirds of all carers do not receive this assessment in the UK. None of the carers interviewed reported having had a carers’ assessment. Research suggests that up to a third of these carers will be depressed and may experience reduced life expectancy and up to 63% of older carers are more likely to die within 4 years than non-caregivers. Research shows that older couples in particular should be assessed as a unit and interventions should be focused on both individuals simultaneously (Shultz and Beach 1999). It is also recognised that a delivery model that focuses exclusively on the person with dementia is not appropriate in dementia care as carers/families need to be considered as ‘partners in care’ as they commonly deliver the majority of the care (Nuffield Centre on Bioethics 2009).

Carers’ stress is associated with their poor mental and physical health; it can impact on the quality of their relationship with loved ones including the person they are caring for, can negatively affect their ability to continue in their caring role, and can precipitate residential care placement for the person with dementia. The literature suggests that after diagnosis, even early diagnosis, subsequent assessment of cognition in the individual with dementia is not a sufficient indicator for caregiver burden. Even if cognition levels remain unchanged the frequency of day-to-day problems could increase and this will increase caregiver burden. This indicates that assessment of cognition needs to be supplemented with assessment of ‘psychosocial disability’ to enable a more comprehensive assessment of caregiver burden. Evidence demonstrates that interventions aimed at individual carers and families do help to significantly reduce carer stress, especially if implemented early and maintained. Interventions such as carer support and counselling at diagnosis and early provision of support at home can help delay and ultimately reduce care home placements.

Accessing help may not be straightforward for carers “because of a lack of knowledge about how the ‘system’ works” (Nuffield Centre on Bioethics 2009 p 122). Services offered also may not be accepted, and while in part this is associated to how carers view their caring role and personal traits, it is suggested that it is also associated to social isolation and the stigma of dementia particularly evident in those living in a disadvantaged community. Gainey et al (2010) suggests that community based initiatives that provide ‘one stop’ gateways are needed that support care services and promote social integration and reduce stigma.

The ‘tipping point’ for care home placement is caregiver burden whereby the carer can no longer physically or emotionally cope with providing safe 24 hour care that the person with dementia needs. Issues contributing to this ‘tipping point’ include:

- Stress
- Sleep deprivation
- Increased frequency of day to day problems and crises
- Challenging behaviour
- Lack of practical and emotional support
Modern dementia policy and research advocate a shift from a medical approach to dementia care to enable innovative psychosocial and re-enablement models of care to be adopted. This new paradigm consists of person-centred holistic approaches, with application of a social model of disability and positive risk management, whereby the person with dementia and their carer are active partners in the care process so that innovative and less medical approaches of care, i.e. psychosocial and re-enablement models of care, can be adopted. This can lead to redefining dementia as a manageable disability. However, whilst policy adopts this paradigm current service provision lags behind with regard to models of delivery, capacity and skills. The current workforce is considered too small and with insufficient knowledge and understanding to provide the high quality dementia care that is needed. Training alone, it is identified, is not enough on its own as it will not improve the care in organisations that do not value good care (APPG on Dementia 2009).

There are some significant shortfalls in capacity and skills in health and social care sectors which will continue to exist. The economic downturn will continue to affect provision from a range of sectors; the Alzheimer’s society, for example, have recently amended their focus from carers to the individuals living with dementia and from individual home visits to group activities and support. The health and social care reforms will have far reaching and at the moment unpredictable effects on services and have already influenced some significant changes in services as the personalisation agenda develops. This is a period of significant change in health and social care and whilst it may be a disconcerting and difficult period it also presents some great opportunities for innovation and will provide some particular opportunities for greater involvement from the voluntary sector in service planning, design and delivery.

Local Carers

For this project nine carers were interviewed using a predetermined interview guide resulting in 8 hours of recordings for analysis. Whilst the limitations of this small number of interviews is recognised, the findings do provide a useful snapshot of caring for those living with dementia in Hull and also correlate very well with themes identified in the current literature.

Those interviewed included 7 primary carers, all spouses and all over 65 years old (3 men and 4 women), and 2 adult children (both women) who were secondary carers. For four primary carers (3 men and one woman) the person they cared for was now in residential care, but they continued to see themselves as carers and they all visited the care home daily for a number of hours and were involved in daily care activities for their spouse. For the remaining 5 carers their relative with dementia was being cared for at home primarily by their spouse. Seven of the individuals with dementia were diagnosed with late onset dementia (over age 65); one had a prior diagnosis of Parkinson’s disease; two had been diagnosed with early onset dementia (under age 65). At the time of interview the period of time since the dementia had been
diagnosed ranged from 3 years to 9½ years. The period of care at home for dementia (prior to residential care placement in some instances) ranged from 3 years to 8 years. 7 of the 9 carers interviewed reported having had contact with the Hull Memory Clinic. Most stated that the person with dementia had already received a diagnosis before attending the clinic, e.g. from their GP or via an emergency hospital admission, but more detailed assessments and more explanations and information about the diagnosis were provided by the clinic.

In the interviews carers discussed their fear of this disease and how the prospect and subsequent reality of a dementia diagnosis was devastating; they recognised the significant impact it would have upon their everyday lives and their hopes for the future. They reported that receiving a diagnosis did not automatically lead to access to appropriate services. They also said that they were not always fully aware of the nature, causes or likely progression of the dementia the person they were caring for had. Carers’ initial perceptions of the disease were usually based upon their previous experiences with dementia or from media presentations of the disease. They were unaware of any risk factors for dementia other than old age perhaps or some family history of dementia; the association of dementia to lifestyle, deprivation, atherosclerosis and diseases such as Parkinson’s Disease were not really recognised.

Whilst carers interviewed could usually pinpoint a specific time when significant and noticeable changes occurred that necessitated medical assessment or intervention, it was only with hindsight that they could see that there was evidence of the disease being present much earlier, even years earlier. The changes identified varied and were usually quite subtle at first and some had thought these were just part of the normal ageing process and not a disease or condition, and consequently there was no thought given at all to assessment or diagnosis. This realisation caused some of the carers considerable distress even today, because of the missed opportunity for early diagnosis and intervention, i.e. earlier intervention that may have prevented the rate of decline perhaps, and because they had treated this individual’s memory lapses as wilful or annoying. Carers acknowledged that it could be hard to accept the diagnosis, once provided; they could not always understand why it had happened or they needed to find a reason for it.

The carers did consider dementia as life-shortening to some extent but perhaps not significantly so, as they also expected to be a carer for many years. They did associate it with complex needs and high levels of dependency but not necessarily with increased risk of physical health problems for the person with dementia. They did also acknowledge that the unpredictability and extent of impact this disease would have on the daily lives of the person with dementia and themselves and on their relationship was not easily understood at the outset. Many carers see their caring role as part of their personal commitment to that individual and a natural expectation of their relationship with that person - “for better for worse, in sickness and in health”. Most carers, particularly spouses, see residential care placement for the person with dementia as a last resort and only to be instigated when the caring situation in their own home becomes impossible, usually meaning physically impossible. However, carers do not seem to give much thought as to when or how such a situation might arise, and rarely have contingency plans in place in case of crisis.

Carers also do not always sufficiently recognise the possible negative impact caring can have on their own mental and physical health and wellbeing. Research suggests that social isolation in particular can lead to increased caregiver burden. Carers stated that they found it difficult to identify when they were no longer coping and were suffering from burnout and needed to be prompted to consider this. It is also recognised that carers may also see seeking help as an
admission of failure; similarly, they often associate residential care placement with their failure as a carer.

What do carers want and need?

A key message from local carers about their needs is that one size does not fit all – dementia is a very personal journey for both the person with dementia and for their family and carers. They agree that the aim of interventions and resources for them as carers for people with dementia should

- Enable them to continue caring for the person with dementia in their own home for as long as practical
- Enable them to maintain a caring relationship between them and the person with dementia
- Enable them to feel fulfilled and satisfied in their caring role

They also agreed that they wanted the best possible quality of life for the person with dementia - for them to be able to live as normal a life as possible, whether in their own home or a care home. They acknowledged that there was a period of re-adjustment for both the person with dementia and their carers when a person with dementia returns home from a period of institutional care and additional support may be needed at this time.

Many carers also recognise that some of the ‘personality’ changes attributed to the dementia in the person they are caring for can sometimes be a result of depression, boredom, frustration, misunderstandings and feeling overwhelmed by what seem unfamiliar surroundings and what are now difficult tasks. They want active help and support that will stimulate the lives of the person they are caring for as well as providing stimulation in their own lives. Having the opportunity to address the changes in sexual intimacy in their relationship is also important to many couples.

The carers conclude:

- No one service can provide for all their needs or the needs of the person they are caring for.
- They recognise there is a key support role that voluntary organisations and volunteers can provide that differ significantly in nature and context to statutory services, and which emphasise empathy, befriending, consistency, reliability, quality and flexibility, e.g. crisis intervention.
- Carers want a variety of services from a variety of providers with better definition of roles and services.
- They recognised the potential of assistive technologies especially in early disease, when implemented together with good care.
- They wanted services that are planned, developed and delivered with significant involvement from carers and people living with dementia.
- Carers reported poor communication between services and service users and poor coordination and communication between services, including poor record keeping. They want better coordination and communication and suggest carer (home) held notes.
- Carers felt it was a constant battle to find out what services were available and then to be able to access them, and then they often felt let down and frustrated by services. Having to constantly tackle service delivery issues impacted significantly upon carers’ stress and their own health and wellbeing and ultimately upon the care they provided. They want a simple way to find out about and access services and information at all stages on the carer journey.
• Some concern was expressed regarding variation between centres, services and areas - that it was a ‘post code’ lottery. Carers wanted to know what constituted best practice and how equity could be achieved.
• Carers’ frustrations were in the main with the management and coordination of services rather than with the individuals who provided the care. They frequently encountered a ‘buck passing’ attitude, a lack of transparency and accountability from ‘faceless professionals’ regarding ‘gatekeeping’ of services and poor service.
• Regarding the individuals providing formal care, carers felt that on the whole they had good relationships with them. They did feel that some care staff were better educated, aware and familiar with dementia than others and some were more caring than others. They wanted some minimum standards for dementia education and awareness established and monitored.
• Carers acknowledged that advance care and end of life care planning was difficult but nevertheless they wanted help and support to do this early enough to involve the person living with dementia and to avoid crises.
• Carers felt they had a wealth of experience and expertise that they could share with other carers and with professionals that would provide support and education but that would also help to promote social integration and reduce stigma, e.g. working with schools. However, they did not think that this expertise was sufficiently valued or made best use of.
• Carers said they gained great strength from the experiences of their peers and from setting up their own support ‘groups’ or discovering individual ways to gain support, however, they did not want to be left with ‘self-discovery’, and they would also appreciate some facilitation of this process, e.g. signposting and support.

Carers said they wanted (and needed) education and support
• About the disease
• About what it is like for the person with dementia
• About services and benefits
• About mental capacity and power of attorney, wills, advance care planning, advance directives and resuscitation
• About what might help me, including counselling
• About making difficult choices and decisions and negotiating with the rest of the family
• About how to communicate effectively with the person with dementia
• To be involved in educating others – formal carers and professionals
• About the sort of things that would really help keep people at home.
• About new skills
• About assistive technologies
**Recommendations**

**Local developments**
- Local policy has already identified that “Investment is needed in local public health campaigns to reduce people’s risk of developing dementia in later life......What’s good for your heart is also good for your head” (YHIP 2010 p9). This may also be an opportunity to involve carers in developing and delivering local health promotion activities.
- Develop advance care and end of life care planning processes and skills so that these are included early on in an individual’s disease journey and whilst they maintain some capacity.
- Carers suggest that poor communication and record keeping could be prevented through the use of carer (home) held notes that they could contribute to.
- The battle/fight that carers describe to find out what services are available and then to be able to access them must be tackled. Again this initiative could be led by carers and those with dementia to identify simple ways to find out about the condition, what services are available and how they can make use of them.
- Key workers/family advocates could provide timely support - face to face and a friendly voice at the end of the phone - that can discuss issues directly with the carer and the person with dementia and facilitate decision making and informed choice and signpost to other services. This support could be provided in the long term and could be provided by a range of organisations - especially voluntary organisations such as HCHfH - but with some agreed key standards implemented regarding boundaries, education, knowledge and information.
- More memory services will be needed to facilitate early diagnosis and timely support for the person with dementia and their carer.
- Involve carers and ex-carers in training and education for ‘new’ carers and professionals (staff and volunteers) - recognise and facilitate access to this resource for carers for support and advice and seek to maintain its independence.
- Educate and support GPs, primary care teams and staff in acute hospitals regarding dementia; education to include recognition and diagnosis of dementia, how dementia progresses and prognosis, models of care and communication and to raise awareness of the services available locally (to include voluntary services) and their responsibilities for ensuring consistent care for all.
- Be aware of the impact that traumatic events, e.g. Flooding, can have upon the care of those with dementia.

**Recommendations for HCHfH**

The way forward for HCHfH is to build upon what they already do so well.

HCHfH is very well apprised of its role and future potential in the personalisation agenda through all its services and its collaborative and integrated approach; this recent dementia project is a direct result of this awareness. HCHfH has an excellent track record for vision and innovation and articulates very clearly its current provider role with regards to personalisation - but also recognises its role as an educator and advocate for users and its role in positively influencing service development and delivery to help ensure services “that are nearer to what service users and their carers want and need.” (Dickinson and Glasby 2010 p24).

HCHfH also perhaps has a particular role to play in developing and supporting expert carers’ initiatives, advance care and end of life care planning processes and in supporting telecare/telehealth initiatives.
HCHfH is recognised for its short term support and volunteer befriending roles that promote independence and its ability to be flexible and respond quickly to a crisis. The impact volunteers can have on social isolation, especially through providing support in a person’s own home, is well recognised; they provide emotional or personal support, often described as a ‘listening ear’ or ‘social visits’ (Bower et al 2006). However, because of the nature of dementia HCHfH would need to develop longer term befriending relationships with carers looking after someone with dementia and the person they were caring for - perhaps identifying these as key workers or family advocate roles. These HCHfH carers support services would not be not be as intense as its short term services and would extend beyond the key worker role, but would provide regular and consistent support (face to face and by phone) to all members of the family, but with particular support provided to the primary informal carer. However, capacity to deliver periods of more intense support at times and the ability to respond to crises would also need to be developed as part of these services and befriending roles.

Access to these HCHfH carers’ support services should not just be related to a formal diagnosis of dementia and should be initiated when memory problems are necessitating some informal care. The befriending role, together with information and support, may help carers and the person with dementia come to terms with what is happening in their lives and may help facilitate with presentation for assessment and diagnosis. HCHfH support could also facilitate advance care and end of life care planning. The support from HCHfH would need to continue through times of transition, which may require some intense support, and afterwards too - e.g. at diagnosis, or when residential care placement is being considered/implemented for the person with dementia. Support provided to carers after residential care placement of the person with dementia would be orientated to helping carers adjust and would focus particularly, perhaps, upon promoting independence.

HCHfH would also be an excellent partner in collaboration with other services, e.g. The Alderson Resource Centre, to develop active outreach and crisis intervention services.

HCHfH is also an excellent resource for advice and support and facilitative signposting to other services and would have a clear role in health promotion activities.

HCHfH will need to clearly identify the services it can support that complement existing provision and that it can sustain, which will lead to the development of an appropriate strategy to address these in a timely and measured way. The following list of services and activities should be considered:

- Developing a dementia care education pathway for staff and volunteers
- Providing an ad hoc respite/sitting service
- Providing regular/scheduled short term respite/sitting service - e.g. time limited intervention, 6-8 weeks
- Providing regular less intensive but longer term support
- Providing practical help and support
- Providing crisis support
- Supporting quality time between the person with dementia and carer
- Providing support specifically to the carers – befriending, listening ear but over extended periods of time
- Supporting carer involvement in service development and education - and could help to develop education initiatives and education pathway for carers
- Developing appropriate routes for referral/signposting to other agencies and services – and helping to improve communication between services
- Advocating on behalf of carers and people with dementia
• Contributing to raising awareness of dementia
• Supporting psychosocial activities – reminiscence work
• Promoting and facilitating advance care, crisis and end of life care planning
• Providing education and support regarding the use of assistive technologies
• Supporting carers and their families through the decision making process regarding care home placement
• Continuing carer support after care home placement
• Support carer and the person with dementia with ‘a day at home’ from a care home if appropriate
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