

# **Report of the Select Committee on Dementia**

## Chair's Foreword

Dementia is undeniably one of the most frightening of all illnesses: to lose aspects of one's memory and the ability to act rationally is an awful prospect, and many of us who have witnessed the effects that dementia has had on our family and friends can attest to how devastating a condition it can be.

Even in the recent past the impact of dementia was often made worse by the fact that it was a condition that people did not speak about: the stigma that attached to mental illnesses meant that many people with dementia and their carers felt lost and isolated, uncertain what support was available and how to access it.

In the past few years much has changed for the better: health and social care services have begun to work together more effectively; the dementia 'care pathway' – the way in which different aspects of dementia care are integrated with each other – has been re-designed to make it easier to understand and negotiate; the Alzheimer's society and other organisations have been tireless in championing the cause of people with dementia. Most importantly, society has begun to hold a mature conversation about dementia; and, although there is still a long road to travel, there is now hope that we are beginning to break down the secrecy and stigma which still cloaks the illness, moving towards recognising it as an issue for communities as well as for individuals and their families.

How we deal with dementia over the next few years is going to be crucial. Whilst there is a very real chance that medical research will develop effective treatments in the relatively near future, we cannot afford to be sanguine: with the average age of the UK population increasing, dementia is likely to become an even more urgent problem than it is today. We have to get better at dealing with dementia and do so quickly. There is much work going on both nationally and locally to achieve this aim, and we hope that this Select Committee report will contribute in some way to this. Even if dementia cannot be cured in the foreseeable future, we can, as a society, strive to ensure that people with dementia and their families receive the support and understanding that they need and deserve.

I would like to thank all the people who took time to give evidence to the Select Committee, and particularly thank Kathy Caley and Carey Wright, who attended every meeting and offered us invaluable support and advice.



Councillor Pat Hawkes, Chair of the Dementia Select Committee

## **Executive Summary**

Anyone looking at the issue of dementia is bound to be struck by how much is currently going on. Ideas about curing, treating and supporting people with dementia have rapidly evolved in recent years. In part this is because the prevalence of dementia is growing quickly as the average age of our population increases, making finding solutions to the problem even more urgent. In part, it is also because we are becoming better at understanding dementia; and, although there is as yet no cure for the condition, huge advances are being made in the field of disease-modifying treatments for diseases causing dementia, including Alzheimer's disease. These advances offer the possibility that effective prevention of or a cure for dementia may be developed in the relatively near future.<sup>1</sup>

For the moment, however, the focus, in terms of the recently published National Dementia Strategy and local strategies which complement it, is largely on providing practical support for people with dementia. Select Committee members are pleased to say that they have been able to make a number of sensible and practical recommendations intended to help the city commissioners of health and social care improve services for people with dementia. There is much, much more to be said about dementia – too much for any single review to deal with. And there is certainly an argument for scrutiny to re-visit this issue in the future, perhaps with a really strategic examination of local services and their outcomes and how they compare with those of neighbouring areas. A future review might also usefully focus on the ongoing research to prevent or find a cure for dementia, particularly in terms of the innovative local work led by Brighton & Sussex University Hospitals Trust.

However, this review has had a pragmatic focus, looking at how local services can be maintained and improved. Detailed explanations of the recommendations are included in the main report, but in brief they are:

- 1 When re-designing the local dementia care pathway, the city commissioners should ensure that all city healthcare workers are appropriately trained in dementia issues, in order to improve early diagnosis of dementia. This should specifically address the issues of GP expertise and that of people working in the acute sector, given the key role that these workers play in the diagnosis of dementia.**

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<sup>1</sup> Information provided by Dr Dennis Chan, Senior Lecturer in Neurology and Honorary Consultant Neurologist, Brighton and Sussex University Hospitals Trust. More information on recent developments in the treatment and prevention of dementia can be found in the (USA) report: A National Alzheimer's Strategic Plan: the Report of the Alzheimer's Study Group (2010).

- 2** That whatever model of memory assessment service model the city adopts, the commissioners should be able to demonstrate that the service: a) provides a homely environment for diagnosis and/or assessment; b) has the capacity to deal with all referrals in a timely manner; c) is able to maintain its core focus if integrated within a team with broader responsibilities.
- 3** That in re-designing the local dementia care pathway, the city commissioners should explicitly address the issue of carer bereavement, ensuring that dementia services support carers as well as people with dementia, and that supports services do not cease suddenly following the death of patients.
- 4** That in re-designing the local dementia care pathway, the city commissioners should explicitly address the issue of how the wishes of people with dementia and their carers can best be reflected in terms of planning appropriate end of life care.
- 5** That the city commissioners should seek to ensure that all their staff and the organisations they commission (e.g. equipment providers as well as health and social care providers) are aware of the need to treat bereaved people with understanding and sympathy.
- 6** When the city commissioners make their decisions on the future of in-patient acute dementia beds, they should bear in mind the position of dementia Select Committee members: that locating this service outside the city should not be agreed unless there are overriding therapeutic benefits to such a move.
- 7** The city commissioners should be able to demonstrate that they have planned for sufficient capacity in terms of in-city nursing and residential home placements to ensure that everyone with dementia who requires such a placement is normally able to access one.
- 8** That NHS Brighton & Hove should arrange the invitation of a representative of the Access Point to forthcoming Locality GP meeting(s) or otherwise facilitate the promotion of the Access Point's work amongst city primary care practitioners.
- 9** That the Access Point should continue to be encouraged to promote its services via all appropriate council/city initiatives (such as Get Involved Day etc.)
- 10** When re-designing the local dementia care pathway, the city commissioners should specifically address the issue of support service capacity in the light of anticipated growth in demand for these services in the near future.

- 11 When re-designing the local dementia care pathway, the city commissioners should explicitly address the issue of ensuring that all aspects of the pathway are as easy to negotiate as possible, so as to reduce the pressure on advocacy and advice services.**
- 12 The city commissioners should investigate the potential benefits of engaging with local communities in order to encourage them to better support people with dementia and their carers.**
- 13 When re-designing the local dementia care pathway and commissioning city dementia services, the city commissioners should specifically address the needs of people with early onset dementia, ensuring that appropriate support services are in place to deal with current and likely future demand.**
- 14 The issue of dementia and the ongoing changes to local dementia services should inform Overview & Scrutiny work planning, particularly with reference to the work programmes of the Adult Social Care & Housing Overview & Scrutiny Committee (ASCHOSC) and to the Health Overview & Scrutiny Committee (HOSC).**

Most of the above recommendations are intended to inform the ongoing partnership project to re-design the local dementia care pathway. This project is expected to be completed in Autumn 2010, and to be ratified by the Joint Commissioning Board shortly thereafter. It should therefore be possible to report back on the implementation of the Select Committee recommendations in early 2011.

This type of scrutiny report – i.e. making a series of recommendations to inform the design of a commissioning strategy, care pathway etc. – is likely to become much more common when the council moves to its 'Intelligent Commissioning model'. For Overview & Scrutiny to work effectively with a commissioning system, it is particularly important that scrutiny work is synchronised with commissioning cycles, so that scrutiny reports influence the development of commissioning plans rather than reporting when a strategy has already been finalised.

## **Introduction**

In 2009 the Overview & Scrutiny Commission decided to form a Select Committee to investigate issues relating to dementia services in the city. The immediate context for this decision was the publication of a new national Dementia Strategy<sup>2</sup> and the imminent re-design of the local dementia care pathway<sup>3</sup>.

Select Committees can be established either for major pieces of work or for work which cuts across Overview & Scrutiny committee boundaries. Dementia is just such a cross-cutting issue, as dementia services directly involve both health and social care and can impact even more broadly. The Dementia Select Committee therefore sought members from the Adult Social Care and Housing Overview & Scrutiny Committee (ASCHOSC) and the Health Overview & Scrutiny Committee (HOSC), as well as other backbench Councillors with a particular interest in this subject. The Select Committee also included a representative from the Brighton & Hove Local Involvement Network (LINK), the city's main representative body for members of the public wishing to engage with health and social care issues.

Dementia presents perhaps the single biggest single challenge to health and social care services in the foreseeable future, with the number of people suffering from dementia expected to increase rapidly over the next few years. Furthermore, the situation with regard to dementia is extremely fluid, with national and local policies being rapidly developed in very uncertain financial and political circumstances. Given this background, it was never really possible that this Select Committee should provide a definitive review of dementia services<sup>4</sup>. Nor was it intended that this review should be principally strategic in its focus: there might well be considerable value in a strategic review of city dementia services, but the local dementia care pathway is currently being revised, as are all mental health services provided by the Sussex Partnership NHS Foundation Trust (SPFT), the main provider of statutory services for dementia across Sussex. Whilst this certainly provides an opportunity for scrutiny to feed into strategies in development, it also makes it rather difficult to run a strategically-focused review, there being no established medium-term strategy or service model to scrutinise and no 'stable' high-performing service in Sussex to benchmark local services against.

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<sup>2</sup> Living Well With Dementia: A National Dementia Strategy; Department of Health, 2009.

<sup>3</sup> A 'care pathway' describes a way of looking at, and designing services for particular conditions which aims to make access to each aspect of the care provided, and the transitions between various types of care, as simple and logical as possible, even when a number of different organisations are involved in delivering that care. In recent years, care pathways have become an integral part of UK health and social care planning and commissioning.

<sup>4</sup> This mirrors experiences at neighbouring local authorities. In West Sussex, for example, Overview & Scrutiny members have been involved in three separate reviews of dementia services in the past 3-4 years.

Therefore, given these issues, Select Committee members decided to limit the scope of their investigation and to make mainly practical rather than strategic recommendations. Generally, these recommendations are intended to support the city commissioners in their ongoing task of revising the local dementia care pathway (working together with a range of partners to achieve this). The Select Committee offers its recommendations with the important caveat that there is much more work to be done on this issue, particularly in terms of evaluating the effectiveness of the local dementia strategy, scrutinising funding for Brighton & Hove dementia services and overseeing the SPFT 'Better By Design' reconfiguration, which may include significant changes to the provision of some city dementia services, particularly in terms of acute bed capacity and/or location.

The Select Committee was made up of Councillors Dawn Barnett, Pat Hawkes, Averil Older and Georgia Wrighton, and Robert Brown, Chair of the Brighton & Hove LINK Steering Group. Councillor Hawkes was chosen to be the Select Committee Chair.

The Select Committee held four evidence-gathering meetings in public, as well as several private scoping meetings. Amongst the witnesses were Brighton & Hove City Council officers responsible for Adult Social Care services; commissioners from NHS Brighton & Hove; clinicians and managers from the Sussex Partnership NHS Foundation Trust; representatives of the Alzheimer's Society and witnesses who had direct experience of caring for people with dementia.

The Select Committee did not interview staff from Brighton & Sussex University Hospitals Trust (BSUHT). In part this was because the focus of this review (in line with the focus of the National Dementia Strategy) was on assessment and support services, rather than the research, diagnosis and treatment services typically provided by acute hospital trusts. In part though it was because scrutiny support staff advising the Select Committee were insufficiently aware of the key role that BSUHT plays in the local dementia care pathway, particularly in terms of specialist services providing diagnosis of young onset and atypical dementias, and in terms of a number of clinical research initiatives.<sup>5</sup> In hindsight, we should clearly have involved BSUHT in the work of the Select Committee.

The Select Committee would particularly like to thank Kathy Caley, Commissioner for Long Term Conditions and Independence for Brighton & Hove, and Carey Wright, Community Mental Health Team Manager for the Sussex Partnership NHS Foundation Trust. Kathy and Carey supported the Committee throughout the scrutiny process, and their input was greatly appreciated by committee members.

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<sup>5</sup> Information provided by Dr Dennis Chan, Senior Lecturer in Neurology, Brighton & Sussex University Hospitals Trust.

The following report begins with a general explanation of what dementia is and the national and local problems it poses, followed by the Select Committee's recommendations and the reasoning behind them.

## **Information on Dementia**

### **What is dementia?**

Dementia is the term used to describe the effects of a group of conditions which progressively affect people's memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. The best known and most common cause of dementia is Alzheimer's disease, but there are several other conditions which cause dementia in significant numbers of people.<sup>6</sup> Other types of dementia include: Vascular Dementia (sometimes known as multi-infarct dementia); Dementia with Lewy bodies (DLB); Alcohol Induced Persisting Dementia; Frontotemporal lobar degeneration; Creutzfeldt-Jakob disease; Dementia Pugilistica; and Posterior Cortical Atrophy. It should be noted that dementia is not in itself a disease: it is the state brought about by a number of diseases, such as Alzheimer's, which each have distinctive pathological and cognitive signatures.<sup>7</sup>

The effects of dementia can vary considerably according to the stage that the disease has reached. People with mild or moderate forms of dementia may well be able to live relatively independent lives providing they have appropriate support; people with severe dementia may well require round the clock care. At any one time, most people with dementia exhibit 'mild' rather than 'moderate' or 'severe' manifestations of their condition (although the older a person is, the more likely it is that their dementia will be of the moderate or severe type). It is estimated that around two thirds of people with dementia live in the community, and around one third in residential or care homes.<sup>8</sup>

### **Causes**

Dementia is caused by the conditions listed above. Some of these conditions may have a genetic links, but others (including Alzheimer's) seemingly do not. It is also well established that poor health, particularly in terms of diet and/or

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<sup>6</sup> Evidence provided by Dr Chris Smith, Specialist Registrar in Psychiatry in Old Age, Sussex Partnership NHS Foundation Trust. See minutes to the Select Committee meeting of 12 June 2009.

<sup>7</sup> Information provided by Dr Dennis Chan, Senior Lecturer in Neurology, Brighton & Sussex University Hospitals Trust.

<sup>8</sup> Dementia UK: the Full Report: Albanese/Banerjee, 2007: p34. The ratio of people living in the community to those in residential care decreases as age increases, and more people over 90 with dementia live in residential care than live in the community. This may be because dementia tends to be more severe amongst older people and/or because older people are less likely to be able to call on carers to help support them at home, and/or are more likely to have co-existing physical problems which restrict their ability to live independently..



cardio-vascular health, can significantly increase the likelihood of developing some dementias.<sup>9</sup> Excessive drinking may also be a significant factor in developing some conditions which lead to early onset dementia, although it is not considered to be a significant factor in developing dementia in general.<sup>10</sup>

## Age

Dementia is generally associated with older people, and is most prevalent in the oldest populations. It is estimated that 1 in 14 people over the age of 65 has dementia, with this figure rising to 1 in 6 of over 80s.<sup>11</sup> Given this strong correlation with age, one would expect dementia to be more of a problem at times when the average age of the population increases or in areas with lots of older people.<sup>12</sup>

Some types of dementia affect younger people, although these 'early onset' dementias are currently relatively uncommon, with only around 15,000 people currently diagnosed in the UK.<sup>13</sup>

## Morbidity

'Late onset' dementia is, in contrast to early onset dementias, a relatively common condition, and its incidence is set to rise as the average age of the UK population increases. It is thought that at least 700,000 people currently suffer from dementia across the UK. It is estimated that, by 2038, this will have risen to around 1.4 million people. As well as having a devastating impact upon people's quality of life, dementia also significantly reduces life expectancy. Dementia is estimated to contribute to almost 60,000 deaths per year.<sup>14</sup>

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<sup>9</sup> For example, it is estimated that up to 50% of dementia cases have a vascular health component. See Living Well With Dementia: The National Dementia Strategy: p27.

<sup>10</sup> See evidence from Dr Chris Smith, Specialist in Psychiatry in Old Age, Sussex Partnership NHS Foundation Trust, 12.06.09: point 4.7.

<sup>11</sup> Dementia UK: The Full Report: p2.

<sup>12</sup> There is a considerable variation in the prevalence of dementia across England, ranging from 0.51 per 100 people in Newham, to 2.09 per 100 in Torbay. The national average prevalence is 1.1 per 100 people (Dementia UK: the Full Report p25).

<sup>13</sup> Dementia UK: the Full Report p27. Early onset dementia is not predicted to increase as rapidly as late onset dementia, as it is not linked to an ageing population. However, some early onset dementias, such as Korsakoff's Syndrome, are linked to excessive alcohol consumption, so increased levels of hazardous drinking across society may impact upon early onset dementia morbidity.

<sup>14</sup> Dementia UK: the Full Report, p37.

## Sex

Approximately twice as many women as men are living with late onset dementia. However, this imbalance is thought to be mainly due to demographics (there are more elderly women than there are men, and dementia is most prevalent amongst the elderly) rather than any greater susceptibility in women.<sup>15</sup>

## Ethnicity

It is currently unclear whether late onset dementia is more prevalent amongst any particular ethnic groups. However, it is anticipated that dementia rates will rise far more quickly amongst some minority ethnic groups than across the population as a whole, as the age profile of some of these groups is significantly higher than for the general population (the bulk of immigrants to the UK in the first wave of mass immigration in the 1950s and 60s were young adults; this cohort is now in its late 60s and 70s - the age groups most likely to develop dementia.)<sup>16</sup>

## Treatment

Dementia is incurable and worsens as the condition progresses. However, there are some drug treatments which may work to slow or even temporarily halt the progress of the disease in some patients. The best known of these drugs is marketed in the UK as 'Aricept'. The use of drugs to treat dementia is a relatively recent development but one which has considerable potential to change radically medical approaches to dementia in the relatively near future. In particular, there are a number of drugs currently undergoing late phase clinical trials which may have true disease-modifying potential.<sup>17</sup>

However, the current NHS position is essentially that medical treatments for dementia are of relatively limited value and should be used only in a minority of cases. This position is based upon an objective analysis of evidence by the National Institute of Clinical Excellence (NICE). NICE collates evidence on the effectiveness of treatments and maps this against cost and the improvement they can make to people's quality of life in order to determine whether to approve treatments or not. There is therefore likely to be little value in lay people challenging NICE's analysis of the efficacy of particular treatments.

However, Select Committee members did feel that it was worth stating that they believed it was important that the threshold for dementia treatment was

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<sup>15</sup> Dementia UK: the Full Report, p31. Considerably more relatively young men (e.g. aged 65-69) have late onset dementia than do women, by around a factor of 1.4/1; but as people get older, this ration is reversed: in the over 90s category for instance, there are more than three times as many women with dementia as there are men.

<sup>16</sup> Dementia UK: the Full Report, p36.

<sup>17</sup> Information provided by Dr Dennis Chan, Senior Lecturer in Neurology, Brighton & Sussex University Hospitals Trust.

set fairly low (i.e. that treatments such as Aricept should be offered even when there was relatively weak evidence of their efficacy), given the impact of the condition on sufferers, their families and their communities. NICE is due to review treatments for dementia in 2012, which is also when the patent period ends for currently licensed dementia drugs (meaning that prices should fall as any manufacturer can produce generic versions of drugs not protected by patent), so it may well be that there is a general move towards providing treatments on the basis of benefits to patients and families rather than on a cost basis.<sup>18</sup>

## Financial Impact

Dementia has a major impact upon health and social care budgets. The Government estimates that the cost of dementia services is currently around £17 billion per annum, a figure which is set to rise to over £50 billion by 2038<sup>19</sup>. To put this in context, the total 2009 budget for the NHS was approximately £110 billion. If rates of dementia grow as anticipated and unit costs do not diminish, the NHS will struggle to provide the current level of dementia care in the future, even assuming that healthcare budgets will continue to rise in line with or faster than inflation.

## The Future

As the average age of Britain's population grows, so conditions such as dementia are likely to become much more problematic, in terms both of their impact upon individuals, families and communities and of their financial impact upon health and social care services. It is widely recognised that current services for dementia are expensive and by no means as good as they might be; without a major re-design it is certain that they will not be able to cope with the anticipated increase in demand.

The NHS has identified dementia as a key national health challenge, and the Department of Health has issued a National Dementia Strategy aimed at improving dementia services across England. Local Primary Care Trust (PCT) areas are also expected to develop their own dementia strategies and care pathways. Re-design of the Brighton & Hove dementia care pathway is an ongoing piece of work.

## Local Issues

In local terms, Brighton & Hove is bound to experience many of the same problems as other parts of the country. However, as noted above, the incidence of dementia closely maps the age of a population, and Brighton & Hove is unusual in having an age-profile that is not expected to rise very much in the medium term. On the face of things, this should mean that city dementia

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<sup>18</sup> Information provided by Dr Dennis Chan, Senior Lecturer in Neurology, Brighton & Sussex University Hospitals Trust.

<sup>19</sup> Living Well With Dementia: The National Dementia Strategy: p9.

services will not experience the same pressures as services in many other parts of the country. However, this has to be balanced against other demographic factors such as the relatively high ratio of very elderly people in the local population (the over-80s are the group most likely to contract dementia, the group most likely to manifest severe forms of the disease, the group most likely to experience complicating co-morbidities, and the group least likely to be supported by carers), and other factors such as poor general health across communities (poor cardio-vascular fitness is a factor in developing some forms of dementia). Currently, approximately 2.6% of city residents are aged 85+, in comparison to a national average of 2.1%. By 2031 it is estimated that around 9% of people in Brighton & Hove will be 85+, compared to an average nationally of around 3%.<sup>20</sup> In any case, even if Brighton & Hove faces less of a challenge than many areas in terms of the capacity of its dementia services, the challenge of improving services is still a very considerable one.

Other local issues which will be touched on later in this report include the city provision of nursing home places for people with dementia, the relatively high costs of city Older People's Mental Health (OPMH) services, and the local provision of in-patient acute mental health beds for people with dementia.

## **Dementia Services**

### **Prevention**

Whilst research to find effective treatments for dementia is ongoing, there is little expectation that a 'cure' will be discovered in the very near future. Given this, how are services going to be improved?

One major focus is likely to be on prevention.<sup>21</sup> Although it might not always be possible to prevent the appearance of dementia in an individual, it may be feasible to delay its appearance across populations - for example by encouraging better diet or lifestyles which minimise the risk of having strokes (both poor diet and cardiovascular health are key risk factors for certain types of dementia). If the onset of dementia across the population could be delayed for an average of five years, this would halve its prevalence, improving many thousands of lives and drastically reducing the potential financial burden on health and social care services.

This is clearly an important area, and one in which Overview & Scrutiny should be engaged. However, for the purposes of this report Select Committee members felt that most if not all preventative health work which might have a positive impact upon dementia had a broader remit rather than being specifically dementia-focused - i.e. in terms of campaigns to encourage

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<sup>20</sup> See the Annual Report of the Brighton & Hove Director of Public Health 2009: Dr Tom Scanlon. P48.

<sup>21</sup> See Living Well With Dementia: The National Dementia Strategy: pp28, 29.

healthier eating, smoking cessation, sensible drinking, cardio-vascular health etc. These issues are probably best dealt with by general scrutiny of city Public Health services rather than via the Dementia Select Committee.

## Diagnosis and Support

The other major focus is likely to be on supporting people with dementia to live full lives. This has a number of aspects. Firstly, it assumes that dementia will be diagnosed at a relatively early stage, whilst the effects of the illness are still relatively mild<sup>22</sup>. Early diagnosis significantly increases the opportunity to enable people to cope with more severe manifestations of their condition. For obvious reasons this becomes much harder as cognitive impairment and memory loss get worse. A similar point can be made about supporting carers: if people with dementia are diagnosed at an early stage, their carers can be appropriately trained and supported; if diagnosis occurs further down the line and carer support has not been provided, the carers may be 'burnt out' by the time that support arrives. If dementia is only diagnosed when people suffer a crisis, then it may often be too late to support them or their carers effectively.<sup>23</sup>

However, it seems currently to be the case that there is little effective early diagnosis of dementia, since it is estimated that only around 30% of people with dementia ever have their condition diagnosed<sup>24</sup>. This means that the majority of dementia sufferers and their carers are left to cope without the most appropriate support, and it also means that the cost of dementia care is increased (as late diagnosis is strongly correlated with heavier use of residential care services, which tend to be considerably more expensive than community support).

Why are diagnosis rates so poor? In part this may be because of the stigma which still attaches to dementia – people are reluctant to acknowledge that they have cognitive or memory problems because they don't want to admit to themselves or others that they may have dementia. People therefore often try and develop coping mechanisms to disguise their worsening mental states. Such coping mechanisms may not be much help in making people's lives easier, but they may well be enough to ensure that medical or social care professionals fail to accurately diagnose their condition.

In part it may also be because the principal contact that most people have with the medical profession is with their GPs, and there are problems with GP diagnosis of dementia. These problems include the length of GP appointments (these have actually increased in recent years, but still average

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<sup>22</sup> It now seems widely accepted that early diagnosis of dementia once symptoms begin to manifest is a good thing. There is however still a debate about whether pre-symptomatic diagnosis (e.g. through people with no symptoms of dementia arranging to have brain scans etc.) is useful or whether it risks 'medicalising' people for no good reason. See evidence from Dr Chris Smith, 12.06.09: point 4.7.

<sup>23</sup> See evidence from Alan Wright, Alzheimer's Society, 17.07.09: point 9.7.

<sup>24</sup> Living Well With Dementia: The National Dementia Strategy: p17.

less than 15 minutes, which is clearly not long enough to do much other than to deal with the ostensible problem with which the patient is presenting); the fact that the great majority of GP appointments take place in GP surgeries rather than patients' homes (it is generally held to be easier to make an accurate assessment of someone's mental health when seeing them in their own home, as many people find the process of visiting a doctor highly stressful and may act in atypical ways, whether or not they have any underlying mental health condition); the fact that patients (and often their partners/carers) will try and conceal cognitive/memory problems from GPs (or will simply eschew GP services in order to hide these problems); and the fact that older people (and especially the 'old old' – i.e. 80 plus) may quite naturally evince some of the symptoms of dementia (e.g. occasional confusion, forgetfulness etc.) whilst generally being in full control of their faculties.

It may also be the case that GPs have been historically reluctant to diagnose dementia because they believe that there is little point in so doing as there are inadequate high quality services to refer people onto, or because they are not always fully aware of the range of services available (particularly in terms of non-NHS support services provided by Social Care or '3<sup>rd</sup> sector' organisations). Indeed, if proper support is not available, a diagnosis of dementia can itself aggravate problems, as poorly supported patients may well suffer from increased anxiety and/or depression occasioned by their diagnosis rather than by their organic mental health condition.

Finally, it maybe that GPs simply tend not to be as good as they might be at diagnosing dementia - although a high percentage of a GP's caseload is likely to feature mental health problems, many GPs have traditionally not been as well versed in mental health matters as they are in general health.<sup>25</sup> The Select Committee asked NHS Brighton & Hove to contact city GPs and invite them to give evidence. However, no GP came forward, and Committee members were told that this was may have been because no city GP was comfortable with presenting themselves as an 'authority' on dementia.<sup>26</sup> However, it may equally have been because GPs were busy or because some of them did not hear about the invitation in time. It is, nonetheless, a matter of concern that there appears to be no city GP with a specialism or even a particular expertise in the field of dementia, and it does seem as if this is an area where NHS Brighton & Hove could do more to encourage the professional development of the GPs it contracts with, although it must be acknowledged that PCTs have often very limited means of influencing local GP practices to do things not stipulated by their contracts.<sup>27</sup>

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<sup>25</sup> See evidence from Louise Channon, 15.01.10: point 20.3-20.6.

<sup>26</sup> See evidence provided by Kathy Caley, Commissioner for Long Term Conditions and Independence, in the minutes to the Select Committee meeting 17.07.09, point 9.2.

<sup>27</sup> This was true at the time of gathering evidence for this report. However, NHS Brighton & Hove has subsequently appointed a GP lead for dementia. The Select Committee welcomes this advance.

A similar general point can be made about those working in acute healthcare, and particularly the older people's wards of General Hospitals. Given the prevalence of dementia in the 'old-old' population, it seems likely that a significant percentage of elderly people admitted to hospital for falls, general ill-health etc. may also have dementia, but (at any rate in national terms) it seems relatively uncommon for hospital clinicians to identify dementia or refer people into diagnosis services. This may be because of poor training of hospital staff – i.e. staff simply do not recognise the signs of dementia. It may also be because of the pressures that acute hospital staff are under – i.e. staff do not have the time to do anything other than their core jobs. It may also be because staff are not familiar with the dementia care pathway: they do not know how to refer people into dementia services or are not confident that such services exist. It may also be the case that there are pressures on hospital staff to expedite the discharge of their patients which tend to work counter to the holistic well-being of these patients (i.e. referring a patient for dementia assessment is very unlikely to speed up their discharge and may well delay it). In such instances, the 'fault' may lie, not so much with acute hospital staff, as with the local provision of specialist community beds (e.g. Intermediate Care beds) for people with suspected dementia to be discharged into.

The Select Committee did not have the time to talk with officers of Brighton & Sussex University Hospitals Trust (BSUHT) about their staff training in regard to dementia issues. It may very well be that BSUHT is doing more than many trusts to ensure that its staff are aware of dementia. However, given the national picture, it seems likely that there is more work to be done here.<sup>28</sup>

Neither was the Select Committee able to progress the issue of GP training as far as members would have wished. Nor did the Select Committee have the time to ask similar questions about people employed in community healthcare (e.g. district nurses). Whilst the Select Committee has no hard evidence that training in dementia issues across city healthcare is poor, it does seem reasonable to suggest that the bodies responsible for the development of the city dementia strategy should ensure that training is of a high quality, and that it is given to all those who require it, including independent contractors to the NHS (such as GPs).

It should be stressed that there is no intention here to criticise either clinicians or healthcare managers. Dementia has not been a national health and social care priority until relatively recently, and this has inevitably meant that the focus of attention has been on other issues. There is no culpability in this, but it is clear that the situation must change.

**RECOMMENDATION – When re-designing the local dementia care pathway, the city commissioners should ensure that all city healthcare workers are appropriately trained in dementia issues, in order to improve early diagnosis of dementia. This should specifically address the issues of GP expertise and that of people working in the acute**

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<sup>28</sup> See Living Well With Dementia: The National Dementia Strategy: pp51-55.

**sector, given the key role that these workers play in the diagnosis of dementia.**

### **Specialist Diagnosis/Assessment<sup>29</sup> Services**

Even if the dementia training of primary and acute healthcare workers were to be improved it might not be enough to solve the problem of poor diagnosis/assessment of dementia; it could be argued that effective early assessment and diagnosis will only be achieved via a dedicated service – essentially this is the Department of Health’s position as set out in the National Dementia Strategy.

The National Strategy proposes creating local dementia diagnosis/assessment services. However, the model for these services is to be determined locally rather than nationally imposed. There are several possible models for an assessment service, ranging from a dedicated site-based specialist memory assessment and support team (as piloted in Croydon via the Croydon Memory Service); through dedicated teams which works alongside Community Mental Health Teams: CMHTs (as piloted in East Sussex via the East Sussex Memory Assessment and Support Team: MAST); to a community-based service delivered by suitably trained CMHTs.

Memory assessment models differ in several ways, including whether they are discrete units or integrated into larger teams; whether they are community based or situated in a clinic; whether they formally diagnose dementia or refer diagnosis to specialist clinicians; and in terms of the degree to which they offer support services in addition to performing assessment/diagnostic duties.

The Select Committee took evidence from the East Sussex Memory Assessment Team (MAST). Deborah Becker, Team Leader at MAST, explained that the service was set up in 2006 as a pilot project to work with people experiencing relatively mild memory problems.<sup>30</sup> MAST carries out short-term intervention work with these clients, aiming to make an accurate assessment of people’s care and support needs and to signpost the relevant services for them. MAST has the capacity to assess people in their own homes, which can be advantageous, as it is generally the case that people will feel less stress in their home environment and therefore act as they normally do, facilitating accurate assessment. When people are assessed in more stressful environments (e.g. hospitals), they frequently act in atypical ways, making it much more difficult to get an accurate picture of their needs.

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<sup>29</sup> Dementia assessment services do not necessarily make formal diagnoses of dementia, in large part because they do not necessarily have consultant psychiatrists as part of their teams. However, in practical terms, this may be largely irrelevant: dedicated assessment teams should be highly skilled in recognising the symptoms of dementia, and their activity is therefore likely to improve diagnosis rates whether or not they refer to hospital consultants to make actual diagnoses.

<sup>30</sup> See evidence provided by Deborah Becker at the 17.07.09 Select Committee meeting, points 9.4 and 9.5.



Whilst MAST is a dedicated memory assessment and support team, it is co-located with the East Sussex Community Mental Health Teams. The Select Committee also heard from Russell Hackett, Director of Business Development at Sussex Partnership NHS Foundation Trust (SPFT), on the subject of memory assessment services. Mr Hackett confirmed that the MAST model was SPFT's preferred model of memory assessment service across Sussex: the trust would like to run such clinics at six sites across the patch, including a clinic in Brighton & Hove<sup>31</sup>. Clearly, however, the final decision on the model for local memory assessment services will not be made by providers alone, but by the city commissioners after consultation with local providers.

It is quite evident that current memory assessment and support services, both nationally and locally, are inadequate. It is equally evident that some form of improved memory service is needed to serve every local area. However, it is not nearly so clear which model of memory service would be best suited to Brighton & Hove. Any new service has to effectively integrate with the current configuration of local services; as these differ widely from area to area, it is unlikely that any single memory service model is going to prove a successful fit in every local health economy.

Moreover, 'ideal' service models have to fit with actual NHS and local authority finances: with the expectation of very significant real terms cuts to NHS and council budgets in the coming years, and the likelihood that local commissioners will also be looking to reduce expenditure, particularly on services where the local spend is significantly higher than national or regional averages or than the spending of comparable organisations – e.g. Older People's Mental Health services. It may therefore not be practical to roll out very expensive memory services (e.g. based on the 'Croydon' model), even if such services were proven to be most effective.

The Select Committee does not therefore propose to recommend any particular model of memory assessment services, as the local decision on the model to be adopted should properly be the result of a complex piece of work by health and social care professionals, balancing the needs of people with memory problems together with the unique configuration of local services and the budget available for this initiative.

However, members do feel that their research qualifies them to make a couple of suggestions in relation to memory assessment services.

In the first place, members believe that there are considerable advantages to assessment delivered in people's own homes or in a homely environment. As noted above, hospitals and GP surgeries can be very stressful places for people to attend, particularly people who fear that they may be developing dementia. On the other hand, the Select Committee heard that one of the most successful aspects of the Croydon memory clinic was that it was co-

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<sup>31</sup> See evidence from Russell Hackett, Director of Business Development, Sussex Partnership NHS Foundation Trust, 12.06.09: point 4.5.

located with the local Alzheimer's Society services, meaning that people with memory problems and their carers could access a range of assessment and support services in one place.<sup>32</sup> However, it may not be absolutely necessary to have a dedicated building-based memory service in order to take advantage of close links to the Alzheimer's society etc: really good signposting of 3<sup>rd</sup> sector services might be just as effective, as might co-location of these support services with CMHTs etc.<sup>33</sup>

Secondly, it is very important that people who are diagnosed with dementia, as well as (at least some) people with memory problems who are diagnosed as not having dementia, and people who are unwilling to be diagnosed (e.g. people who do not want to have brain scans etc), are supported by assessment and support services in a timely fashion. A failure to do so significantly increases the risk of people developing problems with anxiety, depression and social isolation. GPs who encounter lengthy waits when they try and refer their patients into memory assessment services are unlikely to be convinced that they should continue to be pro-active in diagnosing dementia. Therefore, any local assessment service needs to have the capacity to deal with demand promptly.

Thirdly, a memory assessment and support service needs to be well publicised and easy for health and social care professionals to refer into, so as to encourage as many people as possible to use it. At least part of the problem with dementia services as they are currently configured is that the pathway of care and support is not clear, particularly in terms of how people can be referred into the pathway – explaining, to some extent, the apparent reluctance of health professionals to identify dementia. There is potentially an issue here about who should be able to refer into assessment and support services: should it just be GPs, consultants etc? Should it include a much broader range of health and social care professionals? Should it include individuals themselves? (i.e. people could seek memory assessment without having to involve their GP, care workers etc – which might have value for people worried about the stigma of being diagnosed with dementia.)

Fourthly, current practice in the public sector tends not to favour establishing discrete specialist teams, preferring to train generalist workers and teams so that they can themselves deliver much of the specialist input that a dedicated team might provide. There is obviously a good deal to be said for this way of working, and it is central to the development of the Community Mental Health Team model. However, in the context of memory assessment services there do seem to be some real advantages to having a dedicated team available, particularly in terms of the memory service being able to ensure that its staff can concentrate on their core duties.

Therefore, whilst the Select Committee does not seek to recommend any particular model of memory service, it does seem reasonable to recommend

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<sup>32</sup> Evidence provided by Alan Wright, the Alzheimer's Society, 17.07.09: point 9.10.

<sup>33</sup> This already occurs in Brighton & Hove: see evidence from Alan Wright, 17.07.09: point 9.12.

that the commissioners consider the above points when they do choose their preferred model.

**RECOMMENDATION – That whatever model memory service the city adopts, the commissioners should be able to demonstrate that the service: a) provides a homely environment for diagnosis and/or assessment; b) has the capacity to deal with all referrals in a timely manner; c) is able to maintain its core focus if integrated within a team with broader responsibilities.**

The Memory Assessment Clinic model described above does not, in any formal sense, provide diagnoses of dementia. Indeed, it could not, since dementia is not itself a disease, but rather the consequence of a range of diseases. Therefore, while memory clinics can detect the presence of objective cognitive impairment which indicates a state of dementia, they are not themselves sufficient to diagnose the diseases causing dementia. This requires specialist investigation, although not necessarily new services: there are already a number of specialist diagnostic services available across Sussex, mainly provided by Brighton & Sussex University Hospitals Trust and Sussex Partnership NHS Foundation Trust. Improving diagnostic services may therefore principally be a matter of ensuring better collaboration between primary care, mental health and acute neurological services. Brighton & Sussex University Hospital Trust has recently proposed a new model of collaborative working across the local health economy to provide a more comprehensive and integrated diagnostic service.<sup>34</sup> This is not an area that the Select Committee examined, but it is one which the hospital trust was very keen to explore. The Select Committee regrets that it did not do more work in this area: should dementia be the subject of further scrutiny (as the Select Committee recommends), the issue of diagnostic services should certainly be treated in depth.

## **Carers**

Carers are central to delivering effective dementia services. It is the nature of dementia that it can render people exceptionally vulnerable and that it can do so at utterly unpredictable times. Whilst it is certainly possible to support people with mild dementia in the community via professional carer-support, it is much easier (and generally much cheaper) to rely upon partners, friends or family members to provide support, and most people living with dementia in the community do rely principally on 'non-professional' carers. Without this network of carers it is hard to see how support for people with dementia could effectively be delivered, even in terms of the current scale of the problem.

However, for carers to provide an appropriate level of support over the long term, several things need to be in place.

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<sup>34</sup> Information provided by Dr Dennis Chan, Senior Lecturer in Neurology, Brighton & Sussex University Hospitals Trust.

Firstly, it is very important that people with dementia are accurately identified in the early stages of their illness. Without this, people are likely to be fulfilling the role of carer, but without any of the financial or practical support and advice available to official carers. This is bound to diminish the effectiveness of carers and may impact on their ability to deliver care over the longer term. For instance, if people are identified as carers, then the authorities can support them by offering respite, augmenting their care with professional carers, ensuring that they receive all benefits to which they are entitled, sign-posting them to groups where they can exchange ideas and experiences with other people in a similar situation etc. This support can enable people to care for longer and to live fuller lives as care-givers.<sup>35</sup>

Secondly, once people are assessed as having dementia, support for them and their carers has to be readily available and easily accessible. There is little point in aspiring to support carers if the necessary resources are not in place, particularly as a diagnosis of dementia can itself be very unsettling and can lead to serious depression and anxiety both for people with dementia and those close to them.

Thirdly, there is a strong argument for providing appropriate financial support for carers. No one becomes a carer for the money, but many may be forced to relinquish their caring responsibilities for lack of money, and it will almost invariably be the case that this will result in a much greater financial burden on social and health care – the option, essentially, is not whether to support carers properly financially, but whether to support them properly or to pay professional carers much, much more to provide the same levels of support. However, whilst the argument for properly supporting carers is very easy to make in theory, it is evident that the current national financial situation is one which makes increased spending in any sector unlikely in the short term, even if there is a very sound case to be made for spending now to achieve greater savings in the future.

Fourthly, although it is important to think of supporting carers in terms of helping them to give support to the people for whom they care, it is also necessary to think holistically, viewing carers as people with their own needs. For example, carers often compromise their own independence in order to provide care, giving up jobs, tenancies etc. to concentrate on their caring role. If the person being cared for passes away, there is a danger that the carer may find themselves dealing with their bereavement at the same time as finding themselves no longer entitled to financial support etc. There is a clear need here for a care system which supports carers while they are carers and for a reasonable time after their caring responsibilities have ceased.<sup>36</sup>

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<sup>35</sup> See evidence from Alan Wright, 17.07.09: point 9.11.

<sup>36</sup> There may be a specific issue here with day care services. The traditional model of care provision for people with dementia (and others) has typically involved 'day centres' where people with a particular condition are brought together to undertake therapeutic and social activities. These types of service can be regarded as rather old-fashioned and institutionally-driven: centred upon the service providers' convenience rather than the wishes of service users (particularly in the light of the recent moves towards 'personalisation' of social care). There may be good reasons to move away from this type of service, particularly if service

In some instances there are already systems in place. For example, Brighton & Hove City Council's Housing Management service has done a good deal of work around bereavement and has produced a policy which all council employed housing staff must adhere to.<sup>37</sup> Similarly, there is a city carers' strategy which spells out the support that carers should receive.

It is however evident that this support is not always as reliably provided as it ought to be, and that carers of people with dementia are not always as involved in making decisions about their loved ones as they should be.

### **End of Life Care, Death and Bereavement**

There is a particular issue around the death of people with dementia, especially given the extremely close and emotionally intense relationship that can develop between people who live in constant proximity for a long period of time, as is often the case with people with dementia and their carers. It is therefore important that carers are supported and treated with sensitivity when they suffer bereavement.

Sadly, this is not always the case. The Committee heard from Louise Channon, who had cared for her mother for 16 years. Ms Channon told members that, following her mother's death she had been offered no emotional support, and there had been little or no recognition from health professionals etc. of the distress she was feeling. For example, when Ms Channon made arrangements to return 'disability' equipment that her mother had used, the equipment providers made no effort to acknowledge or offer sympathy for her bereavement, despite it being obvious that people returning this type of equipment after long term hire would probably be doing so shortly after the death of a loved one.<sup>38</sup>

Ms Channon also noted that, although she was not personally reliant upon carers' benefits, she felt that the abrupt ending of such benefits once the person being cared for had passed away could potentially be extremely distressing for carers.<sup>39</sup>

Committee members also discussed their personal experiences of dealing with, or helping others deal with, bereavement. One member noted that there could be a particular problem in terms of council tenancies, where a carer who lived with a tenant as their live-in carer, but who was not entitled to succeed to the tenancy, found themselves under pressure to vacate the property when

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users would prefer alternatives – e.g. receiving more services at home. However, day services do provide very important respite for carers, and the carer perspective must be considered when contemplating the re-design of day care.

<sup>37</sup> See 'When a Tenant Dies – Customer Care, Succession and People Left in Occupation', agreed at Brighton & Hove City Council Housing Cabinet Member Meeting, 06 Jan 2010.

<sup>38</sup> See minutes 15.01.10 point 20.13.

<sup>39</sup> See minutes 15.01.10 point 20.13.

the person they were caring for died. Following a history of complaints from tenants, the council's Housing Management service has recently revised its procedures around bereavement and tenancy succession (see footnote 37 above).

There are also issues concerning end of life care, and the degree to which carers and families are involved in planning for the latter stages of their loved ones' lives – i.e. that it may too often be the case that decisions are taken on behalf of people who lack capacity to plan their own end of life journey without sufficient reference to their carers. End of life services are one of the areas currently being focused upon as regional NHS priorities, and the development of regional and local end of life strategies and pathways, particularly in terms of dementia care (i.e. in situations where the person dying lacks the capacity to themselves make their care decisions) should certainly include and involve carers to a high degree.

**RECOMMENDATION – That in re-designing the local dementia care pathway, the city commissioners should explicitly address the issue of carer bereavement, ensuring that dementia services support carers as well as people with dementia, and that supports services do not stop suddenly following the death of patients.**

**RECOMMENDATION – That in re-designing the local dementia care pathway, the city commissioners should explicitly address the issue of how the wishes of people with dementia and their carers can best be reflected in terms of planning appropriate end of life care.**

**RECOMMENDATION – That the city commissioners should seek to ensure that all their staff and the organisations they commission (e.g. equipment providers as well as health and social care providers) are aware of the need to treat bereaved people with understanding and sympathy.**

### **In-patient Beds**

Local health economies need to maintain a relatively small number of specialist mental health in-patient beds for acutely ill patients with dementia (the great bulk of people with dementia who cannot be supported in the community will be placed in nursing homes). In Brighton & Hove these beds are currently provided by Sussex Partnership NHS Foundation Trust (SPFT) at the Nevill hospital in Hove.

It has long been apparent that there are problems with the location of this service: SPFT does not own the Nevill hospital site, and the lease arrangements make it expensive to run. In addition, although the Nevill is not a particularly old hospital, it is a far from ideal environment for people with dementia.

For these reasons, it has for some time been common knowledge that SPFT has been actively investigating other locations for in-patient dementia beds. It is clear that the city's other acute mental health hospital, Mill View, would not be an appropriate location for these beds, since it is generally considered poor practice to co-locate dementia beds with general mental health beds. This essentially leaves four options in the short term: to remain at the Nevill; to purpose-build a new city facility for these beds (surely highly unlikely given the current pressures on NHS capital funding); to co-locate these beds with existing city (general) hospital services; or to re-locate the beds to a site outside the city, presumably an NHS-owned site with lower running costs than the Nevill. (In the longer term it may well be that the local health economy can significantly reduce demand for these beds by more effectively managing community services, enhancing intermediate care provision etc.)

SPFT is currently undertaking a major re-design of its services across Sussex, which will include the reconfiguration of in-patient beds: this initiative is called 'Better By Design'. The Select Committee had hoped to address the issue of the future of dementia beds at the Nevill Hospital as part of its review, as public consultation on changes had originally been scheduled for early 2010. However, the initial timetable for the Brighton & Hove element of in-patient bed reconfiguration has been extended to allow for full canvassing of stakeholder views, and consultation around reconfiguration plans will not now commence until the autumn of 2010.

There are obvious pitfalls involved in taking a view on a possible relocation of services without knowing whether such a relocation is actually being planned, or if it is, what the detailed proposals are. For instance, if plans to relocate dementia beds included a significant enhancement of the therapeutic value of services offered (e.g. to a specially designed environment for dementia rather than to a 'standard' mental health ward), they might appear much more attractive than plans which essentially offered a 'like for like' service in another location.

However, it would surely seem remiss to publish a scrutiny report on dementia services in Brighton & Hove without mentioning this issue at all. In particular, members are very concerned by any plan which would involve the relocation of dementia beds out of the city. Although they may only be used by a relatively small number of people, there is surely a point of principle here: that a city of almost 300,000 people ought to be able to provide all but the most specialised healthcare services within the city, especially for services for the most vulnerable city residents and their families and carers. It seems wholly unacceptable to demand that carers and other family members, many of whom may themselves be elderly and frail, should be required to travel out of the city to visit and support people receiving relatively standard healthcare services. Therefore, whilst the Select Committee would welcome initiatives which sought to reduce reliance upon in-patient dementia beds by improving community services etc, committee members do not believe that there is any justification for relocating dementia beds outside Brighton & Hove, unless perhaps as part of a very significant improvement of service.

**RECOMMENDATION – when the city commissioners make their decisions on the future of in-patient acute dementia beds, they should bear in mind the position of dementia Select Committee members: that locating this service outside the city should not be agreed unless there are overriding therapeutic benefits to such a move.**

### **Nursing Homes**

It is actually far more likely that people with dementia who are unable to cope with living independently will be placed in a nursing home than that they will require a hospital bed. Therefore issues about the adequacy and location of nursing care places are probably more important to most people than issues concerning in-patient bed provision.

In common with the rest of the country, the Brighton & Hove health economy is largely reliant upon relatively small independent sector firms for the provision of nursing care places. This tends to create two potential problems: in terms of the quality of the provision on offer, and in terms of capacity.

The quality of nursing home care was largely beyond the scope of this review. It is clearly an important issue, and there is a quite reasonable concern that small scale independent sector providers may offer services of much more variable quality than the public or corporate independent sectors. However, this may be an issue that is best dealt with in terms of how the commissioners of *all* nursing care places assure the quality of providers (and how they are assisted by national regulators) rather than focusing on issues relating to nursing homes specialising in dementia care ('EMI' homes). It is not clear that there is a particular quality issue with EMI care which might warrant it being examined separately from other types of nursing care. This may be an area that either or both the council's Health Overview & Scrutiny Committee and its Adult Social Care and Housing Overview & Scrutiny Committee wish to pick up on.

In terms of nursing home capacity, relying upon a number of small independent sector providers can also pose problems. It is well established that the number of nursing home places available within a given area can vary according to fluctuations in housing markets, demand for hotels etc. For example, should residential property prices rise, some nursing home owners may be tempted to 'cash-in' by selling their properties for housing. This means that it can be difficult for the local health economy to plan nursing care provision effectively, because this planning may always be undermined by events outside the control of the commissioners of health and social care services.

Should demand exceed capacity, then it may be necessary to commission nursing home places in other areas. Clearly it is not desirable for people to be placed in areas against their wishes, particularly if they have lived in one place for much or all of their lives. (Of course, people and/or their families and



carers may actively choose to be placed in an 'out of area' nursing home: this issue concerns those who may be placed out of area contrary to their wishes.)

There may be ways around this issue. One possibility is for local authorities and/or NHS trusts to themselves provide nursing home services. This might make it much easier to guarantee local levels of capacity over the medium term, as well as making it easier to ensure quality. In some instances it may also reduce costs, although this may not always be the case (i.e. public sector providers may not seek to make unreasonable profits, but on the other hand they generally have higher wage costs etc. than the private sector). In local terms this is also an area where there has been recent positive experience, with the local authority investing in its own residential provision for some services traditionally commissioned from other sectors (e.g. housing for some people with physical or learning disabilities).

Currently, city capacity for nursing care, including specialist 'EMI' care, is generally sufficient to meet demand. Given this, the Select Committee was reluctant to devote too much time to exploring problems which may prove to be of a hypothetical nature. However, Select Committee members do assume that the local health economy is engaged in long term planning on this matter. If not, then there is a clear need for this planning to be undertaken as part of the development of local dementia services – whether this entails the public sector being encouraged to start providing these services or it involves longer term planning and contracting with existing providers. The aim should always be to ensure that there are sufficient in-city nursing home places to cope with the demand, including that for EMI placements.

**RECOMMENDATION – the city commissioners should be able to demonstrate that they have planned for sufficient capacity in terms of in-city nursing and residential home placements to ensure that everyone who requires such a placement is normally able to access one.**

## Housing

The Select Committee did not have time to look in detail at how people with dementia living in the community have their housing needs met. However, members would like to note that this is an area in which social landlords, obviously including the council, could help people to live relatively independent lives in the community for longer by granting them high priority for appropriate types of supported housing: e.g. particularly places on Sheltered and 'Extra Sheltered' housing schemes. These schemes offer general needs housing with additional services such as 'CareLink', warden support etc. and could have an important role to play in supporting people with relatively mild dementia.

It is currently the case that the local Housing allocations system *does* allow for people with overriding medical needs (including needs allied to a diagnosis of dementia) to gain priority access to vacant properties, so the system does already recognise the needs of people with dementia. However, depending on how highly dementia services are prioritised, there is presumably room to alter

the allocations system in order to further encourage people with dementia to use Sheltered and other supported housing. Whilst the Select Committee has no specific recommendation to make in this area, it is certainly something which should be considered when planning dementia services across the city.

### **Better Cross-Service Working**

One of the greatest challenges for health and social care is to work out how best to support people who have multiple needs – e.g. in terms of healthcare, social care, housing support, benefits advice, adaptations for disability etc. Since these services have traditionally been delivered by different organisations or by separate teams within an organisation, it can be very difficult to co-ordinate services effectively. All too often people have to undergo assessment by several different bodies, which can be very frustrating for individuals as well as representing an often unnecessary expense. Perhaps even more seriously, people may never be signposted to a service they could benefit from, because they never hear about it, or because the teams supporting them do not know the entire care system etc. These problems can be aggravated by different services having incompatible IT systems, differing thresholds for taking on clients, different types of team structure etc.

Anyone with multiple needs risks encountering poorly co-ordinated care and support services. However, people with dementia may face particular challenges. This is firstly because they tend to be older people, and are therefore very likely to face multiple challenges, with physical as well as mental health problems (i.e. insofar as older people are more likely to experience general health problems such as poor mobility, breathing difficulties etc). Secondly, the nature of dementia means that it can be very difficult for people, even in the very early stages of the disease, to negotiate labyrinthine health and social care systems. Thirdly, the advanced age of most people with dementia means that they may be socially isolated – unable to draw on the support of friends and family to help them negotiate the care pathway. Even when people do have carers supporting them, the carers themselves may be older people who will struggle to understand opaque care systems.

In order to mitigate the potential atomisation of services delivered across a number of teams and/or organisations, recent years have seen a number of attempts to foster better co-working. Sometimes this may amount to the formal integration of services; in other instances the formation of multi-disciplinary teams or improved ‘whole-system’ training for specific teams. The Select Committee received presentations from three such teams integral to providing support for people with dementia: the Community Mental Health Teams, Intermediate Care Services and the Access Point.

### **Access Point**

The Access Point is a ‘one stop shop’ for people presenting to city social care services. The Access Point team supplies information and advice on social

care issues as well as providing a range of services itself. These include: minor adaptations, repairs and equipment, day services, meals on wheels, CareLink, information on self-directed support, and access to the Daily Living Centre (where people can 'road-test' disability equipment in a 'home' environment).

The Access Point can also assess clients and determine their eligibility for a number of services, saving money and minimising the stress caused by multiple assessments.<sup>40</sup>

Members were impressed by the Access Point and considered it to be an excellent example of a service designed around client needs. Clearly though, for the Access Point to work as effectively as possible, it needs to be very well publicised – people will only use a service like the Access Point if they know that it exists and they understand that it functions as a social care gatekeeper.

To this end the Access Point team has already done a great deal to publicise its service, and these efforts are to be applauded. However, the Select Committee did hear about one specific problem in this context: it seems to be the case that some city GP surgeries do not display information on the Access Point as the practice managers at these surgeries are unwilling to display non-health related information (or information not directly supplied by the NHS).

<sup>41</sup>Whilst it seems perfectly sensible for GP surgeries to limit the amount of information they have on display, it is surely perverse that they should decline to display information on the Access Point, as this is likely to be of considerable interest to many people attending surgeries. Furthermore, there would seem to be an obvious benefit for GPs in making their patients as aware as possible about the Access Point, as a large proportion of enquiries to GPs will probably be social care related. Therefore, GPs who actively promote the Access Point service are likely to find that by doing so they can actually reduce their workload by diverting patients to a more appropriate resource.

It may be that there is a danger of placing too much emphasis on what is a fairly minor problem: it is clear that the majority of city GP surgeries are happy to display information on the Access Point. However, the problem should not really exist at all, and to this end, Select Committee members feel that local GPs might be encouraged to better understand the Access Point and to promote it to their patients.

**RECOMMENDATION – that NHS Brighton & Hove should arrange the invitation of a representative of the Access Point to forthcoming Locality GP meeting(s) or otherwise facilitate the promotion of the Access Point's work amongst city primary care practitioners.**

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<sup>40</sup> See evidence from Guy Montague-Smith, Access Point Manager, 04.12.09: point 14.3-14.6.

<sup>41</sup> Evidence from Guy Montague-Smith, 04.12.09: point 14.8.

More generally, members felt that it was important for the council to support the Access Point, particularly in terms of publicising this service; and key that this support was over the long term rather than fading away after a time. To this end members suggested that they should recommend that the Access Point should be routinely included amongst the council services given the opportunity to promote themselves via events such as 'Get Involved Day'.<sup>42</sup>

**RECOMMENDATION – that the Access Point should continue to be encouraged to promote its services via all appropriate council/city initiatives (such as Get Involved Day etc.)**

### **Community Mental Health Teams**

Community Mental Health Teams (CMHTs) are integrated, multi-disciplinary teams, bringing together nurses, social workers and occupational therapists, and supported by specialist psychiatric services. CMHTs are designed so that they can either directly provide or arrange for all the support that a patient requires, whether in terms of healthcare, social care, help with financial matters, help with housing, arranging housing adaptations etc.<sup>43</sup>

CMHTs are an example of a formally integrated team providing and signposting a wide range of services for clients with particular types of problem. When CMHTs work well, as they often do in Brighton & Hove, they provide a compelling argument for the formal integration of services.

### **Intermediate Care Services**

Intermediate Care Services (ICS) provide residential beds for people who are temporarily unable to live in the own homes, aiding recovery, avoiding needless acute hospital admission and facilitating quicker discharge from hospital. There are currently 61 ICS beds across the city, either in NHS, local authority or independent sector facilities. ICS is also heavily involved in delivering community services, supporting people to live in their own homes.<sup>44</sup>

ICS is by no means a dedicated service for people with dementia, but an increasing amount of the ICS workload consists of clients with dementia, with perhaps two thirds of patients in ICS having either diagnosed or undiagnosed dementia.<sup>45</sup> However, many of these patients will have other issues too – such as mobility problems: dementia is not necessarily always the main reason why these patients are in ICS.

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<sup>42</sup> See 04.12.09, point 14.9.

<sup>43</sup> See evidence from Carey Wright, CMHT Manager, Sussex Partnership NHS Foundation Trust, 15.01.10: point 19.4.

<sup>44</sup> See evidence from Eileen Jones, Intermediate Care Team Manager, 04.12.09: points 14.11-14.12.

<sup>45</sup> See 04.12.09: point 14.5.

In order to better deal with the changing nature of its workload ICS has recently employed a Registered Mental Health Nurse. This nurse is responsible for a number of tasks including supporting ICS staff in dealing with patients with mental health problems; assessing patients already in the service; risk-assessing the service taking on particular patients; and liaising with CMHTs, GPs, mental health advocacy services etc.<sup>46</sup>

Select Committee members welcomed ICS's recognition of the increasing importance of dementia, and its attempts to establish effective relationships with key dementia services. Intermediate Care services are likely to increase in importance in the next few years, in the context of dementia and many other conditions, as NHS commissioners try and decrease the use of very expensive acute hospital beds, and it is important that the local system is geared to make the necessary changes.

It seems very likely that the key to improving city dementia services in the current financial climate lies with ensuring that existing support services work together effectively, integrating where necessary, and avoiding unnecessary duplication whilst retaining important specialist knowledge. It is clear that the actual situation in Brighton & Hove, as in many parts of the country, is still some way from this ideal, and that much work needs to be done. However, Select Committee members were heartened by the examples of really good practice from the Access Point, city Community Mental Health Teams and the Intermediate Care Service described above. It is to be hoped that the city can build on these examples to develop and further coalesce services in the future.

### **Support Services**

As there is currently no cure and relatively few effective treatments for dementia, most interventions seek to support people with dementia and their carers via services like day centres, home help, respite care etc. Many of these support services are provided by 'third sector' organisations such as the Alzheimer's Society. These services are key to ensuring that people with dementia and their carers live relatively full lives, and critically, that people are able to live in the community rather than in residential care – not only does this accord with most people's wishes, but it has very significant cost implications as residential care can be very expensive.<sup>47</sup> However, there are several potential problems with dementia support services.

In the first place, the 'map' of support services that people with dementia can access can be rather complicated, particularly since there is no single service provider.<sup>48</sup> There is therefore the real danger that people will not be aware of services which might benefit them. In part the move to more integrated 'gate-

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<sup>46</sup> See evidence from Dennis Batchelor, ICS Registered Mental Health Nurse, 04.12.09: point 14.4.

<sup>47</sup> See evidence from Alan Wright, 17.07.09: point 9.15.

<sup>48</sup> See minutes to 12.06.09 meeting: point 4.2.

keeping' teams such as the CMHTs and the Access Point should ensure that this problem is minimised: these gate-keepers are aware of the range of services available to people with dementia and should be able to ensure that clients are directed to the most appropriate services. Organisations such as the Alzheimer's Society are also key here: the Alzheimer's Society has an unparalleled knowledge of dementia and is very well placed to help people. The Select Committee was glad to learn that in Brighton & Hove the Alzheimer's Society is already co-located with CMHTs. Innovative close-working arrangements such as this are to be encouraged, and when a local memory assessment service is established it will presumably establish similarly close links with the Alzheimer's Society etc.

Another issue with support services is that of capacity. Even if local capacity is currently not an issue, it may well be in the near future, both because the prevalence of dementia is set to rise (albeit perhaps not as steeply in Brighton & Hove as in other localities), and because improved diagnosis of dementia should mean that many more people present for support services.<sup>49</sup> It is vital that there are sufficient services on the ground to cope with this anticipated spike in demand: diagnosing dementia but then failing to provide appropriate levels of information and support is likely to have a detrimental impact upon service users and their carers. The city commissioners therefore need to be confident that there are sufficient support services in place to cope with both current and likely future demand.

Finally, organisations like the Alzheimer's Society also offer key advocacy and advice services for people with dementia, their families and carers. These services are extremely important, and to a large degree are always going to be needed. However, they are also, at least in part, a reaction to the complexity of dementia services – e.g. if it is necessary to fill in complicated forms in order to access statutory support, then there is an obvious need for advocacy services to help people do this. Therefore, whilst the need for these support services is never going to go away, it might be that making statutory services easier to access will reduce the need for people to rely on third parties to help them negotiate the care system. This is potentially very important in an environment where demand is likely to increase more quickly than resources.

**RECOMMENDATION – When re-designing the local dementia care pathway, the city commissioners should specifically address the issue of support service capacity in the light of anticipated growth in demand for these services in the near future.**

**RECOMMENDATION – When re-designing the local dementia care pathway, the city commissioners should explicitly address the issue of ensuring that all aspects of the pathway are as easy to negotiate as possible, so as to reduce the pressure on advocacy and advice services.**

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<sup>49</sup> See evidence from Alan Wright, 17.07.09: 9.14

## Community Support

In addition to support from the statutory services, from third sector organisations, and fundamental support from carers, friends and family, people with dementia can benefit from local community support. At its most obvious, this might take the form of neighbours checking that someone was OK, helping them with shopping or gardening chores, looking out for them in bad weather etc – i.e. the type of support that traditional communities are often said to have provided, but which has dissipated in modern, atomised, urban environments.

This type of community support would certainly not replace professional support, but it might augment it, improving the quality of people's lives (and perhaps particularly the quality of carers' lives, if they could feel that their caring burden was being shared, even to a small degree). It should also be relatively low cost, an important factor given the likely constraints on health and social care spending in the foreseeable future.

There are some successful instances of these types of community support networks having been developed, particularly in terms of providing community support to people with Learning Disabilities (e.g. the 'Circles of Support' model), and is this type of initiative which might potentially be developed for dementia.

Even if the practical level of community support for people living with dementia and their carers was relatively low, encouraging communities to accept some 'responsibility' for people with dementia might pay major dividends in terms of countering the isolation that many people with dementia and their carers experience. In particular, it might prove effective in raising the esteem in which carers are held - this is an issue commonly raised by carers – i.e. that they perform a difficult and vital role for little or no recompense, and get relatively little recognition of what they do. Better community support might help carers to themselves feel better about the sacrifices they are required to make.

**RECOMMENDATION – The city commissioners should investigate the potential benefits of engaging with local communities in order to encourage them to better support people with dementia and their carers.**

## Early Onset Dementia

Most of this report is concerned with late onset dementia, as late onset dementias affect far more people and are set to increase very rapidly. However, a relatively small number of people will contract forms of dementia characterised as 'early onset' – types of dementia which can manifest in people in their 40s, 50s and early 60s.

Although early onset dementia is not a problem on anything like the scale of late onset dementia, it can be a very distressing condition to deal with, and its morbidity is set to rise (albeit not so quickly as late onset dementia with its close demographic tie), both because some of the societal/environmental

factors which can lead to early onset dementia, such as very heavy drinking, are increasing; and because better diagnosis of dementia is bound to lead to more under-65s being diagnosed.<sup>50</sup>

Given this likely spike in demand it is important that services for people with early onset dementia have sufficient capacity. Even in terms of current demand this is not necessarily the case. For instance, the Select Committee heard about the Towner Club, a support service for younger people with dementia and their carers. The Towner Club has proved extremely successful and is widely regarded as a model for dementia support services. However, it can only accommodate 10 people, which is not sufficient to cope with current demand. If people with early onset dementia cannot be accommodated by the Towner Club, the only realistic options are to offer them support at a service designed for people with late onset dementia or to not offer them any support at all. The latter is clearly very undesirable, and supporting relatively young people via services intended for much older people can also be problematic.<sup>51</sup>

Therefore, when thinking about city capacity for dementia support services, the commissioners should consider the issue of early onset dementia services, and ensure that city provision is sufficient to meet likely demand without having to divert people into inappropriate services.

**RECOMMENDATION – When re-designing the local dementia care pathway and commissioning city dementia services, the city commissioners should specifically address the needs of people with early onset dementia, ensuring that appropriate support services are in place to deal with current and likely future demand.**

### **Future Scrutiny**

It is evident that this is a time of considerable flux for mental health services. On the one hand, we are entering into a period when it seems very likely that there will be extreme pressures on health and social care budgets, with most commentators predicting a long period of austerity. Healthcare commissioners will inevitably have to react to real-terms reductions in funding by looking very carefully at the services they commission, and particularly at those areas where their commissioning spend is higher than national averages, the spend of comparable organisations etc. Sussex Primary Care Trusts have already begun this benchmarking process with regard to mental health, as Sussex spending (particularly in relation to services for older people) is considerably higher than that in many other areas.

The Sussex Partnership NHS Foundation Trust (SPFT) is also undertaking a major review of all its activity, and is expected to make significant changes to the way in which it provides services, potentially including services for dementia. These changes are likely to focus on providing value for money, but

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<sup>50</sup> See evidence from Alan Wright, 17.07.09: point 9.16(b).

<sup>51</sup> See evidence from Alan Wright, 17.07.09: point 9.16(b) and (c).



also on shifting the focus of mental health care from the use of acute hospital beds to a more community-based service.

And, as noted above, demographic change is likely to see an explosion in demand for dementia services across most of the country. Although the effects may not be as severely felt in Brighton & Hove as in East or West Sussex, there is bound to be sharply increasing demand for services in the near future.

For these reasons, it is clear that this review should be considered as the beginning of Overview & Scrutiny's involvement with the issue of dementia rather than any kind of final word. Local dementia services will be evolving very quickly in the coming months and years as ways are found to make less money go further and to help people with dementia and their carers live full and satisfying lives. At this point it is still not clear what reconfigured local services will look like, or indeed whether changes to dementia care will improve things for the people of Brighton & Hove. It is therefore important that Overview & Scrutiny continues to keep a watch on issues relating to dementia – either by constituting further scrutiny panels (perhaps to undertake a more thorough strategic review of local dementia services), or by requesting regular updates to the adult social care and health scrutiny committees.

**RECOMMENDATION – that the issue of dementia and the ongoing changes to local dementia services should inform Overview & Scrutiny work planning, particularly with reference to the work programmes of the Adult Social Care & Housing Overview & Scrutiny Committee (ASCHOSC) and to the Health Overview & Scrutiny Committee (HOSC).**

As is common practice with Scrutiny reports, the recommendations of this report, assuming that they are endorsed by the Overview & Scrutiny Commission (OSC), will then be submitted to the appropriate executive body/bodies for consideration. If recommendations are accepted, then their implementation will be reviewed by OSC approximately six months after their acceptance. Further monitoring will take place at six monthly intervals until the OSC is satisfied that implementation is complete.

Most of the recommendations in this report are intended to feed in to the re-design of the local dementia care pathway. This re-design is expected to be completed in Autumn 2010, with ratification by the Joint Commissioning Board following shortly after. It should therefore be possible to report back on implementation of the Select Committee recommendations in early 2011.

### **Cost**

It is clear that we are living through a time of very real financial uncertainty, with exceptional pressures on all kinds of services. This will undoubtedly include services for dementia: we already know that local spending on Older People's Mental Health (which includes the bulk of dementia spending) is well above national and regional averages and higher than most comparators. In

an era of fiscal restraint, there is therefore bound to be considerable pressure on this and many other budgets.

When drawing up its recommendations, the Select Committee did bear the financial environment in mind: none of the above recommendations are likely to cost very much to implement, and, where there is a cost involved (for example in providing better training on dementia to healthcare staff), there is always a 'spend to save' argument to support the recommendation. That is, a relatively small expenditure at the 'front' of the system (i.e. at assessment stage) is likely to result in greatly reduced expenditure later on (e.g. by supporting people to live for longer in the community and thereby reducing nursing home costs).

The Select Committee has drawn up its recommendations in this way because members wanted to be realistic about what is practically achievable at the present time, and it is evident that proposals to significantly increase expenditure are unlikely to be welcomed, unless there is a clear argument to show that short term cost increases will lead to longer term value for money improvements.

However, Select Committee members do want to be clear that they would oppose any real terms cuts to the dementia budget or dementia services, even in the context of real terms reductions across health and social care budgets. Dementia is such a major problem that cuts would be bound to be counterproductive in the longer term, as well as impacting upon some of the neediest and most vulnerable people in our society. Moreover, the increasing prevalence of dementia means that it is unlikely that even the present standards of support and treatment could be maintained for very long with falling budgets. Committee members do recognise the very difficult job facing the commissioners of city health and social care services, but urge that maintaining dementia spending should be considered a priority.