ScotPHN report

Scottish Public Health Network (ScotPHN)

Dementia Health Care Needs Assessment

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Foreword

Like many of you, I have had personal experiences of dementia and how it affects people. Firstly, there was my father. Many of you will already know the course of events: the early signs that were simply laughed off between us as being everyday forgetfulness; the confusion and the angry frustration when simple things were too much; the slow erosion of a life lived in the world at large, to one that existed in a carefully constructed network of routines that allowed a degree of functioning; and then, the day came when I was no longer a son, just another unrecognised visitor. Being a public health specialist, and one who specialised in the public health of old age, I was aware of the potential avenues of care and how best they could be applied. I could not fault the care that was given, once the diagnosis was made. But it did not make it any easier personally.

Later, I had experience of trying to understand how an older person with a bad case of food poisoning may have contracted the micro-bacterial cause of their illness. As I interviewed them, I became aware that the case history they were giving was inconsistent: that they were not offering any information; simply confirming my suggestions or saying they were unsure. From there I quickly established they were unable to recall even simple things; like if they had eaten anything for lunch. This event helped me to understand just how difficult trying to provide care for an older person with dementia must be, irrespective of whether you are a professional carer or one of the very many “informal carers” that are at the front-line of dementia care.

From the very beginning of the work by the Scottish Public Health Network in developing the Health and Social Care Needs Assessment for Older People in Scotland, creating a new Health Care Needs Assessment for people with dementia has been a priority. So it is with very great pleasure to see it now published and at a time when it can be used in conjunction with the updated Scottish Dementia Strategy.

I would especially like to thank Cameron Stark, Peter Connelly and Suzanne Croy who have been central to the work which has gone into the report, the members of the project group, and my colleagues at ScotPHN who have made the whole thing happen.

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1 Dementia

Cameron Stark and Peter Connelly

> *'Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple cortical functions, calculation, learning capacity, language and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied, and occasionally preceded by, deterioration in emotional control, social behaviour or motivation.'* World Health Organisation (1992)

Scope of the Report

This report is focused on dementia occurring in older people. Early onset dementia, including dementia in the context of a learning disability, is important in its own right and has an enormous impact on affected individuals and their families. The increasing number of older people with dementia has important implications for Scotland, and it is that area that is the focus of this work.

The Syndrome of Dementia

Dementia is a syndrome – a collection of symptoms that occur together. It is not a single disease, and several causes can produce the symptoms that, together, lead to a diagnosis of dementia.

The symptoms of dementia include(1):

Cognitive or behavioural symptoms that:

- Interfere with the ability to function at normal activities
- Are a decline on previous performance
- Are not explained by other psychiatric illness, or by delirium

According to the National Institute of Aging and the Alzheimer's Association in the US, for a diagnosis of dementia, the symptoms should include impairment in at least two of five possible categories:

- The ability to acquire and remember new information
- Impaired reasoning and handling of complex tasks
- Impaired visuospatial abilities
- Impaired language functions
- Changes in personality or behaviour

The diagnosis of dementia is a clinical diagnosis, based on information from the affected person and a knowledgeable informant, accompanied by an objective assessment, including cognition and function. This would not normally include formal neuropsychological assessment, except in cases of doubt.

Types of Dementia

Dementia is usually categorised as being Alzheimer’s Disease Dementia, Vascular Dementia, Lewy Body Dementia and Parkinson’s Disease Dementia, and Frontotemporal dementia with other forms, including alcohol-related dementia, being less common in the population.

Alzheimer’s Disease Dementia

Alzheimer’s disease is named after Alois Alzheimer, a German psychiatrist and neuropathologist who described pathological changes in the brain of a relatively young woman who died after suffering years of memory loss, confusion and language problems. The pathological changes he described were deposits or ‘plaques’ outside the neurons in the brain, and twisted or tangled fibres within the nerve cells(2). These plaques and tangles remain the cardinal pathological signs of Alzheimer’s Disease neuropathology.

> *‘Alzheimer’s first patient had a rather unusual picture, characterised by persecutory beliefs, disinhibition and stereotype behaviour, with an onset in her late 40s and admission to hospital in 1901 at the age of 51. However, Alzheimer concentrated on memory and language in his case presentation, leading to a concentration on these symptoms for many years and the under-diagnosis of Alzheimer’s disease until the 1960s when the keynote papers of Blessed, Tomlinson & Roth began to make clearer associations between neuro-pathological changes and clinical presentations. The likelihood is that his first patient had a single gene variant rather than the much more frequently seen sporadic late onset case.’*
>
> Dr Peter Connelly
> Co-Director, Scottish Dementia Clinical Research Network

It is important to distinguish between Alzheimer’s Disease Dementia, and the neuropathological process of Alzheimer’s Disease. It is now clear that the pathological changes of Alzheimer’s Disease can be present without accompanying symptoms. In this report, the term Alzheimer’s Disease Dementia is used for ‘the clinical syndrome that arises as a consequence of the AD pathophysiological process’(1)(pg. 264). A recent US consensus statement suggests that there should be no age cut off for the diagnosis of Alzheimer’s Disease Dementia, because of evidence that disease in people under 40, and in the very old, can be part of the same patho-physiological spectrum(1).

According to McKhann and colleagues, Alzheimer’s Disease Dementia has the core features of dementia noted above, accompanied by an insidious onset, and evidence of memory impairment or specific problems with other defined cognitive functions.

They recommend the diagnosis not be made in the presence of prominent symptoms of one of the other dementia sub-types.

Van Norden and colleagues provide a helpful summary of the development of current thinking on Alzheimer’s Disease neuropathological changes(3). A British research group identified an association between plaques and tangles and clinical symptoms in the 1960s. Subsequent work identified the amino acid sequence of β-amyloid, and established that it was present in blood vessels in people with Alzheimer’s Disease Dementia, and was also the main component of the plaques described at the beginning of the twentieth century.

Advances in genetics allowed the gene which produces the precursor of β-amyloid to be identified (β-Amyloid Precursor Protein, or APP), and located on Chromosome 21, the same chromosome that is affected in Down’s Syndrome, a condition in which early onset Alzheimer’s Disease Dementia often occurs(4). A sequence was identified in which two enzymes, β-secretase and ɣ-secretase, break off β-amyloid from APP.

Genetic disorders that result in some dementias have added to the evidence that these pathways are involved in Alzheimer’s Disease neuropathological changes. Disorders affecting the presinelins result in greater production of one type of β-amyloid, and are associated with early onset Alzheimer’s Disease Dementia. Apolipoprotein E (apoE) is a gene involved with amyloid clearance. It is possible to have either one, two or no copies of a version of this gene, apoE e4. People with two copies are at considerably greater risk of developing Alzheimer’s Disease Dementia, again implicating amyloid production and clearance in the development of the disease.

One version of the ‘amyloid hypothesis’ suggests that APP is broken down to larger proportions of soluble β-amyloid, or decreased clearance of β-amyloid, which when combined to a specific size (oligomers), then precipitates out in to blood vessel amyloid deposits, and in plaques.

The tangles in Alzheimer’s Disease neuropathology are inside cells, and are mainly composed of tau, a protein associated with structures called microtubules. The amyloid hypothesis suggests that damaging concentrations of β-amyloid may disrupt microtubule formation, and lead to tau accumulation. This may be accelerated by the formation of paired helical filaments of types of tau protein.

Clinical trials of compounds intended to disrupt this purported pathway have not, so far, produced clinical benefit. Disappointingly, trials that reduced plaques did not bring a corresponding improvement in clinical condition although it is, of course, possible that this was because of pre-existing damage. There was no evidence of a slowing of progress, which suggests that multiple elements are involved in the pathway.

There is an overlap between the Alzheimer’s Disease neuropathology in people with symptoms of Alzheimer’s Disease Dementia, and those who are regarded as cognitively normal, or at least as not having a dementia(5). As a result, other hypotheses have developed, including the suggestion that β-amyloid may play the key role in triggering cell death; that presenilin functioning is crucial, or that tau protein plays a causal role, rather than being mainly a consequence of other processes. Inflammation in microglia may also be important. The vascular hypothesis suggests that an interaction between Alzheimer’s Disease neuropathological changes and vascular impairment may precipitate disease, and this is discussed further below.

Vascular Dementia

As with other types of dementia, Vascular Dementia describes a group of disorders rather than one single condition (6). Atherosclerosis of large and medium sized arteries can result in thrombosis, or in emboli which can disrupt blood flow to the brain. Similar changes in small blood vessels can also cause blockages (infarcts) or bleeding (haemorrhages). The resultant damage can be very small, in which case they are termed microinfarcts or microbleeds. Insignificant in their own right, such infarcts and bleeds can combine to cause significant impairment. Amyloid β-protein can also be deposited in the walls of small blood vessels, again causing damage(6).

These changes can produce three main types of Vascular Dementia. In Multi-Infarct Dementia, repeated blockages to blood flow to areas of the brain produce sufficient damage that symptoms become apparent. In some cases, this can occur after one small infarct, because it affects a crucial area of the brain (termed Strategic Infarct Dementia). Finally, disease of small blood vessels can produce a widespread thinning of nerve cells in the area below the outer layer, or cortex, of the brain. This is termed ‘Subcortical Vascular Encephalopathy’, or ‘Binswanger’s Disease’(6). In practice, an individual can have a combination of different lesions. Dementia caused only by vascular lesions is relatively uncommon. Vascular damage is often found in combination with Alzheimer’s Disease neuropathological changes. This may be related in two ways. It is possible that the combination of vascular damage and Alzheimer’s Disease changes can combine to damage enough brain tissue to produce symptoms. It is also possible that there is a link between the two diseases. For example, small vessel disease results in impaired drainage from brain tissues, and increased leakage of proteins derived from blood occurs(6). This may also make it more difficult for β-amyloid and apoE to drain from the brain, thus encouraging Alzheimer’s Disease neuropathological changes(7). This may help to explain the association of cardiovascular disease risk factors, discussed later in the report, with the prevalence of both Vascular Dementia and Alzheimer’s Disease Dementia.

There is reasonable evidence of an interaction between Alzheimer’s Disease neuropathology and vascular damage in the expression of clinical symptoms. One study reported that symptoms in a group of older women were greatest in those who had Alzheimer’s Disease neuropathology, and who also had vascular damage(8). A US study examined people in a cohort study with and without dementia at their final clinical examination, and compared their neuropathology after death. For people with dementia, the most important associations were cortical microinfarcts, severe neurofibrillary changes, and Lewy bodies(9).

Strozyk reported that vascular changes in the white matter of the brain at post mortem were associated with a diagnosis in life of dementia(10). As the presence of this vascular damage increased, so too did the likelihood of a previous diagnosis of

Alzheimer’s Disease Dementia. While different groups have reported varying associations(11,12), there does seem evidence to support an interaction between vascular risk factors and the expression of symptoms in the presence of other brain pathologies, including Alzheimer’s Disease neuropathology.

Dementia with Lewy Bodies and Parkinson’s Disease Associated Dementia

The core clinical features of Dementia with Lewy Bodies are of a progressive dementia with visual hallucinations, fluctuating consciousness and spontaneous Parkinsonism. Sleep disturbance is common. Identifying the condition if possible is important, as people suffering from these diseases are very affected by antipsychotic drugs, which therefore have to be used with great caution(13)(14).

Parkinson’s Disease Associated Dementia appears to be a very similar condition, although extrapyramidal symptoms are less common in dementia with Lewy Bodies (14). Pragmatically, the two conditions are usually distinguished by the sequence of onset, with Parkinson’s Disease Associated Dementia being diagnosed if Parkinson’s Disease symptoms precede dementia symptoms by at least a year(13). In practice, this is a rule of thumb, and a consensus statement recommended making the diagnosis that made the most sense in the clinical context(13).

Dementia with Lewy Bodies is one of a group of disorders known collectively as synucleinopathies. The commonest of these disorders are Parkinson’s Disease, and Dementia with Lewy Bodies (15). In all of the related disorders, there are abnormal accumulations of the protein α-synuclein. In Parkinson’s Disease, and Dementia with Lewy Bodies, this aggregation occurs in the bodies of nerve cells (where the accumulations are known as Lewy bodies) or in neurites. Accumulations of this protein can also occur in Alzheimer’s Disease, and in association with disease known as tauopathies (such as progressive supranuclear palsy)(16)(page 207). Vascular disease is also present in up to 30% (13)(page 4).

There is large clinical variation in the clinical presentation, and it is difficult to distinguish Dementia with Lewy Bodies as a dementia sub-type, and diagnostic sensitivity of clinical examination is low. As with pathological changes in Alzheimer’s Disease neuropathology, it is possible to have widespread Lewy Body distribution in the brain without clinical symptoms(17). It is unclear whether the Lewy Body changes are themselves the cause of the impaired brain function, or if they are a consequence of other brain changes which cause the impairment(17). A consensus statement notes that the best that can be done at post-mortem is to identify the probability that the Lewy Body pathology is likely to have caused the clinical dementia(13).

The prevalence of dementia with Lewy Bodies is uncertain. A recent systematic review concluded that it was not possible to make any reasonable estimate of incidence and prevalence, with prevalence estimates for the proportion of dementia accounted for by dementia with Lewy Bodies varying from 0–30%(18).

Fronto-temporal Dementia

Frontotemporal dementias are a group of disorders characterised by clinical symptoms related to disordered functioning in the frontal and temporal lobes of the brain. The clinical presentation is of behavioural or language dysfunction, with relative preservation of memory in the early stages of the disease(19). The commonest presentation is behavioural disturbance and in the absence of obvious memory impairment, diagnosis can be delayed, with resulting failures in management(20)(21). The behavioural changes can include disinhibition, poor impulse control, anti-social behaviour, stereotyped behaviours and apathy. As people with the disease rarely have insight in to their condition, the reasons why behaviours can be readily misdiagnosed are obvious.

Other presentations include a difficulty in understanding and recalling words while speech remains fluent ('semantic dementia'), and a non-fluent progressive aphasia, although this can also occur in the context of Alzheimer's Disease and cerebrovascular disease(21). Some authors prefer the term 'Primary Progressive Apahasia', to acknowledge the point that similar symptoms can be caused by different disease processes, and that there is not always prominent frontotemporal lobe impairment(22). Generally, about 70% of people with Primary Progressive Aphasia prove to have frontotemporal pathology, and the remainder Alzheimer's Disease neuropathology.

Distinctions in sub-types of frontotemporal dementia are far from clear cut. There is overlap between the behavioural and language dysfunction subtypes(23), and memory problems can be more prominent that some of the historical disease descriptions would suggest.

Frontotemporal dementia tends to have a younger age of onset(24). The disease does occur in older people, but the degree of lobar atrophy tends to be less than in younger people with frontotemporal ementia(25). The relationship of frontotemporal Dementia to other conditions is not clear. Aggregations of tau proteins are very often present in some of the clinical syndromes, but not in others. Conditions such as Motor Neurone Disease, Progressive Supranuclear Palsy and Corticobasal Degeneration are thought by some researchers to be related conditions, but there is no consensus on this(23).

Relative contribution of different pathologies

A Swedish study(26), reporting on autopsies in clinically confirmed cases of dementia, reported that over a thirty year period, pathological signs were of Alzheimer's Disease in 42% of cases, Vascular in 23.7%, mixed Alzheimer and vascular pathology 23.6% and Frontotemporal dementia 4%.

The British Medical Research Council Cognitive Functioning and Ageing Study has reported on 456 people who contributed their brains after death as part of a large longitudinal study(27). The researchers compared the brains of those suffering from, and free from, dementia at the time of their deaths. This study, in a UK group, identifies the prevalence of pathological brain changes at post-mortem, and attempts to estimate the Attributable Risk of each type of pathology to the risk of dementia.

92% had at least mild neurofibrillary tangles in the hippocampus and entorhinal cortex, 52% had at least mild tangles in the neocortex, and 68% some neocortical plaques. Vascular pathology was also very common. At least mild neuropathology was, therefore, very common. There were significant differences between people with dementia and those without. The best predictor of dementia was neurofibrillary tangles in the neocortex, with all individuals with severe tangles having a dementia diagnosis. As in previous studies, there were differences between symptoms and pathology. 13 people had severe neuropathology of various types, but no evidence of dementia, while 68 people had a dementia diagnosis, but generally mild pathological changes. 47% of those who did not have a dementia diagnosis had small vessel disease, and 24% had multiple vascular disease.

The attributable risk for dementia calculated by the investigators was increasing age (18%); small brain (12%); plaques (8%); tangles (11%); small vessel disease (12%); multiple vascular pathologies (9%); hippocampal atrophy (10%); amyloid angiopathy (7%) and Lewy Bodies (3%). The Lewy Body estimate is likely to be an underestimate as the author's acknowledge that their methods were not optimised for the identification of Lewy Bodies.

There are several implications from this study. The treatment of people with any degree of Alzheimer's Disease neuropathology if it could be identified reliably in life would require the treatment of many people who will not develop a dementia. Alzheimer's Disease neuropathology is again suggested to be an important cause of dementia. Vascular disease also emerges as a potentially important factor in dementia in population terms.

Summary

Dementia is a syndrome rather than a single disease. Diagnosis is based on clinical assessment, with information from the affected person, and from a knowledgeable informant.

Pathological changes associated with dementia are very common chance findings in post-mortem examination of older people. Many people who have mild pathological changes have no symptoms of clinical dementia at the time of their death, and some people with relatively severe clinical symptoms have limited brain changes at post mortem, emphasizing the importance of clinical diagnosis.

In the population as a whole, Alzheimer's Disease Dementia, vascular dementia, dementia with Lewy Bodies and frontotemporal dementia are the commonest dementias. Mixed pathologies are very common, with vascular changes and Alzheimer's type pathological changes often occurring together.

2 Risk Factors

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Dementia risk factors are difficult to estimate for several reasons. Research on people who have dementia has the dual problem of obtaining reliable and unbiased estimates of past exposure, and of separating the effects of the disease process itself, from pre-existing risk factors. Health maintenance organisations in the United States, including Kaiser Permanante, have been one source of cohort study.

As a consequence, estimates usually come from cohort studies in which people have been followed up for long periods of time. These cohorts were usually established to research other conditions, such as cardiovascular disease, so the information collected at entry in to the cohort will rarely provide all the information that might now be wanted.

Long cohort studies inevitably have significant drop out, and the people who drop out may not share the same characteristics as those who remain in the cohort. In addition, diagnostic or cut off criteria applied earlier in a long cohort study are likely to differ from those applied now, and it may be difficult to apply contemporary criteria retrospectively.

With dementia, diagnoses will depend on information from the last available interview, from other records, or both. Depending on the frequency of review there may be a significant gap between the last interview round and the person’s death, and so a possibility of the clinical situation having altered.

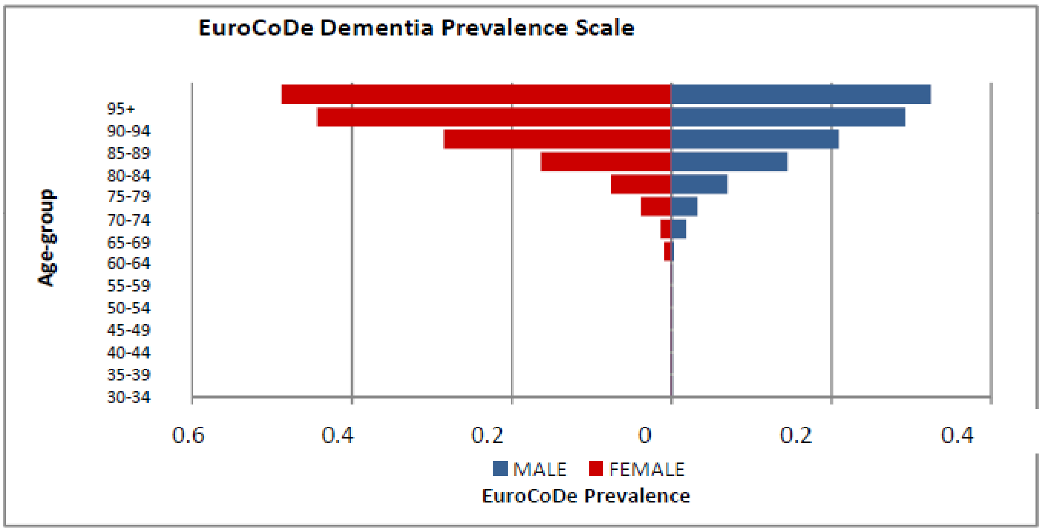
Brain pathology is important in dementia studies, but other than in imaging studies, unavailable until after death. Some people choose to donate their brains after death to allow for further study, but the donation rate tends to be low, and the people who do volunteer to donate their brains may not be typical of the cohort as a whole. Most studies endeavour to describe the comparisons between the cohort participants any original cohort information, and also to compare brain donors with the cohort as a whole.

Age

Age is the single most important risk factor for dementia as a whole. Dementia prevalence increases with age. The Rotterdam study produced the important finding that rates did not appear to level off with age – i.e. there is no window after which risk has passed. This is important, given the increasing age of the population in many countries, and the marked increase in the very oldest old people(28).

Figure 1 shows the age-specific rates from a synthesis of European studies(29), included as part of a wide programme called the European Collaboration on Dementia (known as EuroCoDe).

Figure 1: Age-specific rates of dementia from EuroCoDe Study



Source: EuroCoDe 2009 / NHS Highland Service Planning Department.

Genetics

There are many genetic causes of early onset dementia(30). Autosomal Dominant dementias are those where the person always develops the disease if they inherit the gene from one parent. These can be caused by abnormalities in the amyloid pathway described earlier, including the amyloid precursor rotein gene (APP), and either of the two presenilin genes (PSEN1 and PSEN2). Up to half of families with autosomal dominant early onset Alzheimer's Disease Dementia have mutations to one of these three genes. There are many different identified mutations to these genes that can result in dementia (177 in PSEN1, for example). Although of very great significance to the affected families, only about 0.5% of those with Alzheimer's Disease Dementia have mutations to one of these genes(30).

Population twin studies confirm that there is a strong heritable element to Alzheimer's Disease Dementia (31). In twin pairs, if an identical twin develops Alzheimer's Disease Dementia, the second twin is at significant risk of developing the illness as well, and this risk is higher than in non-identical twins. The risk in identical twins is not 100%, however. This demonstrates that there is significant genetic risk, but that it must be modified by environmental influences.

APOE e4 is one of the best known of the genetic associations with Alzheimer's Disease Dementia(32). It is associated with an increased risk of late onset Alzheimer's Disease Dementia, as opposed to the early onset associated with some other types of familial risk. A US group has reported that there are no pre-existing cognitive differences between carriers and non-carriers before the age of 50, and no differences in rate of cognitive decline prior to 50(33), which gives an indication of why the gene prevalence may have been able to be so high, as it does not affect the reproductive years. One APOE allele, e2, is protective.

In people aged over 50 years who are APOE e4 carriers, there is evidence of a greater decline in memory before the age of 60 years compared to non-carriers, more rapid progression, and some suggestion of a dose-response relationship with greater decline in people with two copies of the allele(33). Despite this increase, some people with e4 / e4 will not have dementia even in very old age, indicating that this is an increase in relative risk.

The population attributable fraction for Alzheimer's Disease Dementia for APOE has been estimated to be a maximum of 25%, and probably considerably less(28). More recent candidate genes include CLU, CR1 and PICALM. CLU codes for Clusterin (also known as Apolipoprotein J). Clusterin is present in amyloid plaques, so is part of a plausible causal pathway. Estimates of Population Attributable Fraction for Alzheimer's Disease Dementia are up to 8.9% for CLU, and 3.8% for CR1, with PICALM at around the same proportion as CR1(30).

APOE continues to appear to be the major genetic risk factor for late onset Alzheimer's Disease Dementia. There is an obvious trend for larger studies being required to identify genes with progressively smaller Population Attributable Fractions, suggesting that the major candidates may have been identified(30).

Hypertension

Several cohort studies have reported on an association between high blood pressure in mid-life and later dementia(34,35). Risk seems to be associated with hypertension in middle age, and there is an association with both Alzheimer's Disease Dementia and vascular dementia. In population terms, an association with Alzheimer's Disease Dementia is important, as it is the commonest dementia pathology, as discussed above.

The Honolulu Heart Program / Honolulu Asia Ageing Study has been used to attempt to estimate Population Attributable Risk of dementia from hypertension (36). This study was in a population of Japanese American men, and recruited people in 1965, when the subjects were aged around 40–60 years. At the time of the initial recruitment, higher blood pressures than now would have been accepted as within a normal range, and this should be borne in mind when interpreting the results.

The authors concluded that, in this cohort of people, around 15% of dementia cases could probably be attributed to a systolic blood pressure >120mmHg. Most of the excess cases came from people with modestly elevated blood pressure, as they constituted a larger population group, and who were less likely to have been treated. Treating high blood pressure was associated with a reduction in risk.

This is one of a number of studies that suggest that untreated high blood pressure in middle age is associated with a substantial proportion of cases of dementia in later life.

Cholesterol

There is a theoretical link between cholesterol levels and dementia, as cholesterol affects amyloid precursor protein breakdown, and also has an important role in vascular pathology. There have been conflicting findings on dementia risk and mid-life cholesterol levels. The Honolulu study described above reported no significant association, nor did the Framingham study(37). However, a Finnish study and two US Kaiser Permanente studies (on overlapping cohorts) have reported an association(34,38-40). The largest of the Kaiser Permanente studies reported an association between increasing mid-life cholesterol levels and both Alzheimer's Disease Dementia and vascular dementia(38). Overall, there was about a 60% increase in adjusted odds ratio with the highest level of cholesterol.

As these conflicting findings would suggest, this relationship is not clear cut. Mielke and colleagues(41) reported that, in a Finnish cohort, there was no evidence of an association between midlife total cholesterol and later dementia. They also found evidence that a decrease in cholesterol in the course of the 32 year follow-up was associated with increased dementia risk.

This may be an example of the issue discussed above in relation to hypertension, with different associations at different parts of the life course. Haan points out that high cholesterol in early and mid-life, and declining cholesterol in later life, may both increase dementia risk(42). On the basis of the available evidence, Haan concludes that it is not possible to give definitive advice on cholesterol and its relationship to dementia.

Obesity

There are three recent systematic reviews on the association between obesity and dementia, one of which includes a meta-analysis(43). In the studies included in the most recent review, two of five studies reported a positive association between obesity and all incident dementia; by two of five studies in relation to Alzheimer's Disease Dementia, and by one of three studies in relation to vascular dementia.

In their meta-analysis, Beydoun and colleagues reported a non-significant 42% increase in risk in dementia in people with a Body Mass Index (BMI) of over 30, compared to non-obese people. The authors felt there was evidence of a U-shaped relationship, with underweight and overweight people both having an increased risk of dementia. They estimated the population attributable risk to be 12% for all dementia, and 21% for Alzheimer's Disease Dementia.

A fourth systematic review looked at vascular risk factors as a whole, including obesity. This study separated the results of studies which measured obesity in mid-life from those measuring it in later life(44). These authors calculate the odds ratio of developing dementia as approximately doubling in the presence of mid-life obesity. As a result of the high prevalence of obesity, they estimate that 26–29% of dementia could be attributable to obesity.

While there are differences between studies, and it is difficult to separate out the independent effects of different vascular risk factors, it does seem likely that there is a population effect of obesity on dementia risk, and that general advice on maintaining a healthy weight continues to be appropriate.

Diabetes

Kloppenberg and colleagues conducted a systematic review and meta-analysis on the risk associated with diabetes, as part of a wider review of vascular risk factors (44). They identified 14 studies that looked at the risk of one or more types of dementia in people with Type 2 diabetes. Five of nine studies looking at risk of any dementia reported an increased risk. Six of eleven and six of ten studies reported an increased risk of Alzheimer's Disease and vascular dementia respectively. Several studies reported an additive effect of diabetes and APOE, hypertension or vascular disease. The authors concluded that the Odds Ratio of developing dementia was just over two and that between 2% and 9% of dementia cases might be attributed to diabetes, although the evidence on glycaemic control remains conflicting.

Atrial Fibrillation

A recent systematic review and meta-analysis reviewed the evidence for an association with dementia(45) . There was evidence that, in people who had a stroke and who had AF, there was a significantly increased risk of developing dementia (2.43, 95% CI 1.70 – 3.46). There was a non-significant increased risk in people with AF who had not had a stroke (1.64, 95% CI 1.00 – 2.71).

Smoking

Studies on smoking and dementia have either been relatively short follow up studies in older people, or longer studies in cohorts established for other purposes. There is wide evidence that tobacco smoking is associated with an increased incidence of dementia. One study reported that this was particularly important in among APOE e4 carriers(46).

A recent study reported on the outcomes in the Kaiser Permanante Multiphasic Health Check-up study, where the original recruitment was conducted between 1978 and 1985. There was persuasive evidence of a dose-response gradient for smoking and later dementia. In a multivariate model which adjusted for other known risk factors, smoking 10 – 20 cigarettes a day was associated with a Hazard Ratio for dementia of 1.37 (1.23-1.52); 20 – 40 cigarettes a day a Hazard Ratio of 1.44 (1.26-1.64), and More than 40 a day a Hazard Ratio of 2.14 (1.65-2.78)(47).

Alcohol

There is no convincing evidence that, at a population level, alcohol use is associated with a greater risk of dementia. There have been numerous reservations about these findings, as alcohol-related brain damage is a well-documented risk of heavy alcohol use. Reasons for concern about these findings include the possibility that results are influenced by people who stop drinking because of ill-health. The earlier death of people with alcohol dependence has also been raised as a possible confounding factor. In addition, some studies account for a large number of papers, and it is important to take account of multiple publication. Other concerns have included the use of studies that did not screen for cognitive status at the baseline, and limited information in some studies on cognitive decline.

A recent meta-analysis sought to take account of some of these concerns, and was particularly careful to exclude duplicate publication or sequential publication of the same cohort(48) . They concluded that light to moderate drinking of alcohol was associated with a 25–28% decrease in risk of development of Alzheimer's Disease Dementia, vascular dementia and 'any dementia'. They found no evidence that heavy drinking was associated with higher rates of dementia, but as most of the groups included in the studies were relatively old at cohort inception, they could not confidently exclude a risk of bias in the findings on heavy drinking.

It seems very likely that light alcohol consumption (1–2 units a day) reduces dementia risk. There is no information, however, on how this interacts with other risk factors, such as ApoE. In population terms, the overall risks and benefits associated with alcohol consumption would have to be taken in to account in making any recommendation on alcohol consumption in the context of dementia prevention.

Anxiety

Anxiety is relevant to dementia in three ways. Anxiety symptoms are common in dementia, and this is discussed later in the 'Interventions' section. Secondly, anxiety symptoms are associated with a greater risk of dementia(49). There are two main possibilities proposed for this association: anxiety may be an early symptom of the pathological processes that produce dementia, or anxiety may affect cognitive capacity, resulting in earlier expression of symptoms. There are several postulated mechanisms for co-occurrence of anxiety and dementia, including disrupted serotonin metabolism, cholinergic mechanisms, HPA axis dysfunction and genetic risk(50). As suggested by this long list of possibilities, there is no certainty about mechanisms.

Beaudreu and colleagues provide a helpful review of anxiety and dementia(50). They note that the presence of anxiety symptoms in older adults is associated with reduced cognitive performance in cross-sectional studies. There is less information from longitudinal studies. Two of the three studies they identified reported an increased rate of cognitive decline in older people with clinically significant anxiety symptoms.

Anxiety symptoms are very common in people with mild cognitive impairment and with dementia(50). People with mild cognitive impairment who have subjective memory impairment and anxiety are more likely to progress to dementia than those without anxiety. Symptoms may be commoner in vascular dementia than in Alzheimer's Disease Dementia, but these symptoms occur frequently in all dementias. Prominent anxiety symptoms in people with co-existing dementia are associated with a greater rate of cognitive decline, and more behavioural disturbance.

Anxiety seems, therefore, to be both common and important in dementia and in mild cognitive impairment. The nature of the association is unclear, however, and the potential role of treatment on progression of cognitive decline is uncertain.

Depression

Depression is common in people with mild cognitive impairment, and with dementia. People who develop dementia have often had a previous depressive illness. Earlier reviews reported significant associations between depression and later dementia, with a relative risk of around two(51, 52). The risk may be greater for more severe depression(53), and for repeat episodes of depression(54).

Recent studies have continued to report an association. Kohler and colleagues, in a follow-up to the Maastricht Aging Study(55) reported that, nine years after assessment on a depression rating scale, people who had originally scored in the upper quarter of low mood scores were significantly more likely to develop a dementia. This seemed to be related to an increase in vascular dementia risk, although dementia type differentiation was based on clinical assessment.

The main controversy is whether dementia increases risk, or whether the occurrence of depression occurs as a prodrome to dementia (i.e. the same pathological process that produces dementia earlier increases the risk of depression, as opposed to depression itself increasing the risk for dementia). As poverty, cardiovascular risk factors, depression and dementia often co-exist; it is difficult to be sure of the direction of association(53). If depression does increase dementia risk, this may be by bringing forwards the expression of dementia symptoms, or by hippocampal damage, which then increases dementia risk. (Jorm et al 2001)

There is markedly conflicting evidence on the key point of direction of association. A meta-analysis by Ownby and colleagues (cited Brommelhoff) reported that the risk of dementia increased as the time since the initial depressive illness increased, suggesting that there is a causal association between depression and later dementia (56). There was considerable heterogeneity among the studies, however, and other research has reached different conclusions.

A recent, elegant, study by Brommelhoff and colleagues used information from a Swedish twin study to explore risk. In this study, people with depression in the previous ten years were almost three times more likely to have dementia, while people with depression more than ten years previously were not at increased risk (57).

Clarifying this relationship is important. Depression is common, and if depressive episodes are a causal risk for dementia, then adequate treatment of depression and prevention of further episodes could be of population importance in dementia prevention, as well as in decreasing morbidity from depression itself. It remains possible, however, that the association is as a prodrome, rather than part of a causal pathway in which depression then increases dementia risk.

Head Injury

Head injuries increase the risk of several neurological sequelae(58). Severe traumatic brain injury may increase the risk of an Alzheimer’s Disease Dementia (59). Moretti and colleagues summarise the findings by pointing out that the most people with dementia have no history of traumatic brain injury, and not all people with traumatic brain injury develop dementia. They suggest that a model where existing injury increases the rate of normal cognitive decline best fits, and that this may be distinct from mild cognitive impairment(60), but this remains speculative.

There is more controversy over the role of multiple mild traumatic brain injuries. Dementia pugilistica, a syndrome associated with boxing, is well described(61), and risk may be affected by ApoE status(62). Professional American football players also seem to have an increased risk of dementia, probably related to repeated blows to the head(63, 64).

Repeated concussions have significant neurological risks, and appropriate management of concussion is important(65). Culture in sport is important, and injuries can be dismissed. Guidelines on concussion are often not followed, but there is evidence that education improves reporting and management(66).

In population terms, a more common scenario is multiple head impacts in sport, without concussion. This is common in soccer, where heading of the ball is a common part of the game, particularly for defenders. An initial paper drew an analogy with boxing(67), and various cross-sectional studies have subsequently reviewed cognitive function in footballers.

Concussion in soccer usually occurs because of collision, rather than because of purposive heading of the ball(68). Work on non-concussive impact, mainly from heading, have produced conflicting results. Earlier studies which reported generally positive associations were criticised on the grounds of selection of control groups, self-report of heading, failure to distinguish between concussion and cumulative effects of heading, and multiple testing of associations without adequate statistical adjustment(69). Studies have reported conflicting findings, both on short-term and long-term sequelae(69-72), in children and in adults. Overall, the evidence was conflicting and unconvincing.

A recent research letter suggested that professional football players showed white matter changes in the brain that were not present in professional swimmers, even in the absence of any history of concussion(73). The significance of the brain changes was unclear.

Further research will be undertaken, given the widespread participation in soccer. At present this remains an area where there is insufficient certainty to be able to offer population advice.

Education and Occupation

A number of studies have reported that a longer period of education is associated with a lower prevalence of dementia in later life(74, 75). Associations were strongest with levels of education that would be unlikely now, such as leaving school at a very young age, so it is possible that additional ‘later’ years of education may have less association than undertaking a basic level of education.

It is not clear if this association is with education in its own right, or if longer years of education are then associated with less exposure to other factors which may increase dementia risk. For example, if greater education is associated with higher socio-economic status, and risk factors such as smoking or uncontrolled hypertension are less common in higher socio-economic groups, then lower rates of dementia could result.

An alternative hypothesis is that education somehow increases ‘cognitive reserve’. In this hypothesis, more pathological change is needed to bring about the same degree of cognitive impairment, therefore offering a degree of protection against the expression of dementia symptoms(76-78). Work from the 10/66 Group in LAMI countries has reported similar findings on education, suggesting that it is a robust finding(79).

A recent study using information from three cohorts, including the UK MRC cohort, provides some information on this(78). The research found that people with less education had the same level of neuropathology at death as people with more education. Those with more education tended to have larger brains, and to be less likely to have a diagnosis of dementia at the time of death (OR 0.89), with evidence of a gradient towards more education/less clinical dementia.

Brayne and colleagues discuss the possible confounding issues(78). It was possible there was a selection effect, for example, with people with larger brains being more likely to undertake more education. It could also be that education results in greater brain weight, for example by means of increased neuronal connections. This work found that the effect of education ceased to be apparent when tangles became very severe, suggesting that there may be a threshold beyond which education is no longer able to be protective. In population terms, however, there is reasonably consistent evidence that more years spent in education is associated with a lower risk of dementia in later life.

Discussions of the effect of types of work are very similar to those on education. Although some authors report no association(80), other studies report a protective association between task complexity and decreased dementia risk, although task complexity may itself be associated with higher education(81, 82). Mentally stimulating pursuits in later life may also have an impact(75). Trials of ‘brain training’ type pursuits demonstrate that performance can improve significantly on tasks, but there is limited evidence of transfer of these improvements to other areas(83,84).

Physical Activity

Two possible effects of physical activity have been proposed in dementia: decreased risk of developing dementia, and slowing of progression in mild cognitive impairment or dementia. A recent US report concluded that there was insufficient evidence to make a recommendation(85, 86), but some authors have argued that this group reviewed an overly narrow portion of the available evidence. (87, 88)

There are several challenges to drawing clear conclusions from the available research. Physical activity, particularly if recalled, can be difficult to quantify. People with existing disease may be less likely to undertake activity, and so reduced activity can be a result of a disease, rather than a cause. Several mechanisms have been postulated, including an effect on vascular disease, and direct effects on cerebral degeneration(87).

A meta-analysis of trials of aerobic exercise in healthy groups reported a modest improvement in psychological measures of cognitive performance(89). Hamer and Chider, in a systematic review of prospective cohort studies, reported that there was a significant decrease in dementia risk in the highest activity category in the included studies compared to the lowest, and that this reduction was present both for dementia as a whole (RR0.72, 95% CI 0.60 – 0.86), and for Alzheimer's Disease Dementia (RR 0.55, 95% CI 0.36 – 0.84). Work by Angevaren and colleagues reported no association in maintenance of processing speed and exercise duration, but an association with exercise intensity(90).

Ahlskog and colleagues discuss a range of individual studies in some detail, including studies suggesting that exercise may produce short-term benefits in people with dementia, with similar effect sizes to Anticholinesterase use(87). Exercise is included in the on-going UK Evidem study. Further evidence is needed on this, but there is a cohesive body of evidence suggesting that exercise may have a preventative effect on dementia incidence.

Social Networks

There appears to be a general inverse relationship between social relationships and risk of death(91). A number of studies have reported an inverse association between social networks and / or social engagement, and the risk of developing dementia(92-95). Fratiglioni and colleagues argue plausibly that education, social networks and physical leisure may have similar mechanisms of action(96).

Bennett and colleagues compared neuropathological changes in people who had died and who had no diagnosis of dementia(97). They found that larger social network size appeared to be associated with increased cognitive functioning for a given level of Alzheimer's Disease pathology at post mortem. Clearly direction of association cannot be confirmed from this study, but it does seem to be in line with ideas of cognitive reserve discussed earlier. (97)

Other Prevention Possibilities

The dementia literature is littered with potentially promising findings. The Rotterdam study raised the possibility that oxidative stress and inflammatory factors might be important in some people(28). The observation of decreased risk with use of non-steroidal anti-inflammatory drugs is intriguing, but its significance is unclear.

Higher antioxidant intake (Vitamin C, Vitamin E, flavanoids) have been reported to be associated with lower rates of dementia in some cohort studies. Findings are conflicting, however. In the Rotterdam study, for example, Vitamin C, Vitamin E and flavanoid intake (the flavanoids being mainly from tea) were reported to be associated with lower rates of dementia at six years follow-up. In a re-analysis at around nine years, however, only Vitamin E retained a statistically significant association, and the authors concluded that the Vitamin C association was probably chance(98). In the light of conflicting findings, it is difficult to make any dementia-specific recommendations on dietary intake.

Summary

Views on the likely efficacy of prevention vary, and different review groups have reached opposing conclusions. On balance, cardiovascular risk factors are likely to be important and advice on stopping smoking, taking exercise and keeping a healthy weight all seem sensible actions in the broad context of a healthy lifestyle. Management of hypertension, and of Atrial Fibrillation, remains important. Encouraging people to remain interested in life, and socially engaged, also seem reasonable advice in both a general context, and in relation to dementia.

The Department of Health's Dementia Strategy took a clear stance on prevention (99) (page 24):

'Inclusion of a strong prevention message that 'what's good for your heart is good for your head'.

This is in line with the Center for Disease Control in the United States, and while it is not possible to be definitive, it does seem justified to advise people that tackling cardiovascular risk factors may also have the effect of decreasing dementia risk.

3 Dementia in the Future

Cameron Stark and Peter Connelly

Introduction

As the risk factor section described, the single largest risk factor for dementia in the general population is age. Projections of the future number of people with dementia are calculated by taking current age-specific rates (e.g. from EuroCode), and applying them to the expected future number of older people.

This is a reasonable approach, and does give a useful estimate. There are several reasons, however, why it should not be assumed to be completely accurate.

Patterns of underlying risk factors

Some risk factors, such as genetic risk, are not amenable to direct intervention at present. Other risk factors can be changed, or have already altered. This includes some risk factors that appear to interact with genetic risk.

The main group of risk factors are those relating to cardiovascular risk. There has been a large decline in cardiac deaths in Scotland(100), with a rate of decrease comparable to other European countries, although from a higher starting position (page 43). The largest contributor to the decline in deaths appears to be risk factor reductions, although treatment has also played an important role(102,103).

There remain substantial inequalities in Scotland. Leyland and colleagues noted that, while many areas in Scotland have mortality rates broadly similar to the mean of other European countries, a third of the population lives in areas with markedly higher rates than the European average(100). The possible reasons for the markedly high rates of mortality and morbidity in some areas of Scotland have been extensively discussed(104-106). While explained partly by deprivation levels, other cultural factors influencing life and behaviour seem to be important.

Within cardiovascular disease, despite the overall fall, socioeconomic differences in younger age groups have not improved(107), or have even increased(108). Inequalities continue in to later life(109) and so evidence of continuing inequalities may be relevant to future rates of dementia in different groups. Prevalence of diabetes and obesity may increase dementia risk in the future.

Years of completed education are also relevant to dementia risk. The school leaving age in Scotland was raised to 14 in 1901, although in some cases primary schools continued to provide all education until 1936, after which all pupils over 12 years of age had the right to a secondary school education. ‘O’ Grade examinations were introduced in 1962, and a leaving age of 16 was implemented in 1972(110). This means that many older people had fewer years of completed education than would be the case now.

Job complexity has also tended to increase(111). This is far from evenly distributed, however, and some jobs in technical processes may be very repetitive(112). An overall increase in job complexity, if the association is causal, could lead to decreased age-specific rates of dementia. Piccinin reported higher initial MMSE scores, but detected no slower rate of decline(113), arguing that previous reports may have methodological problems.

As noted in the risk factor section, there may be a protective effect of higher intelligence in dementia. The much debated Flynn Effect could be relevant to this (114). The Flynn Effect – the steady increase in scores on IQ tests over generations – has been explained by various means. Some authors relate it to test subjects being more familiar with tests and methods(115).

It may reflect a true change, perhaps related to increased cognitive demands(116). There is some evidence if an increase in Scotland(117-119). The increase in the UK has tended to be in ‘fluid’ intelligence (non-verbal and reasoning abilities), and some work suggests that the gains have been greatest in the lower ranges of the ability distribution. Lynn suggests that the pattern of UK gains more persuasively supports improvements in nutrition and decreases in environmental challenges (such as lead in water) as the agent of change(120). How this could play in to dementia risk is unknown.

Given the complex picture of decreases to cardiac mortality and increases to some risk factor prevalence, Rocca and colleagues have reviewed recent US surveys (121). They found that, of four recent studies, three gave no persuasive evidence of a decrease in age-specific dementia rates, although one did report an unexplained decrease in its second study period. A fourth study on measures of cognitive impairment did find a significant decline in prevalence between two study periods ten years apart(121). Other work appears to contradict this, such as the finding in Sweden of an increased prevalence in people aged 85 years and over. The study authors suggest, however, that improved survival may at least partly explain their findings.

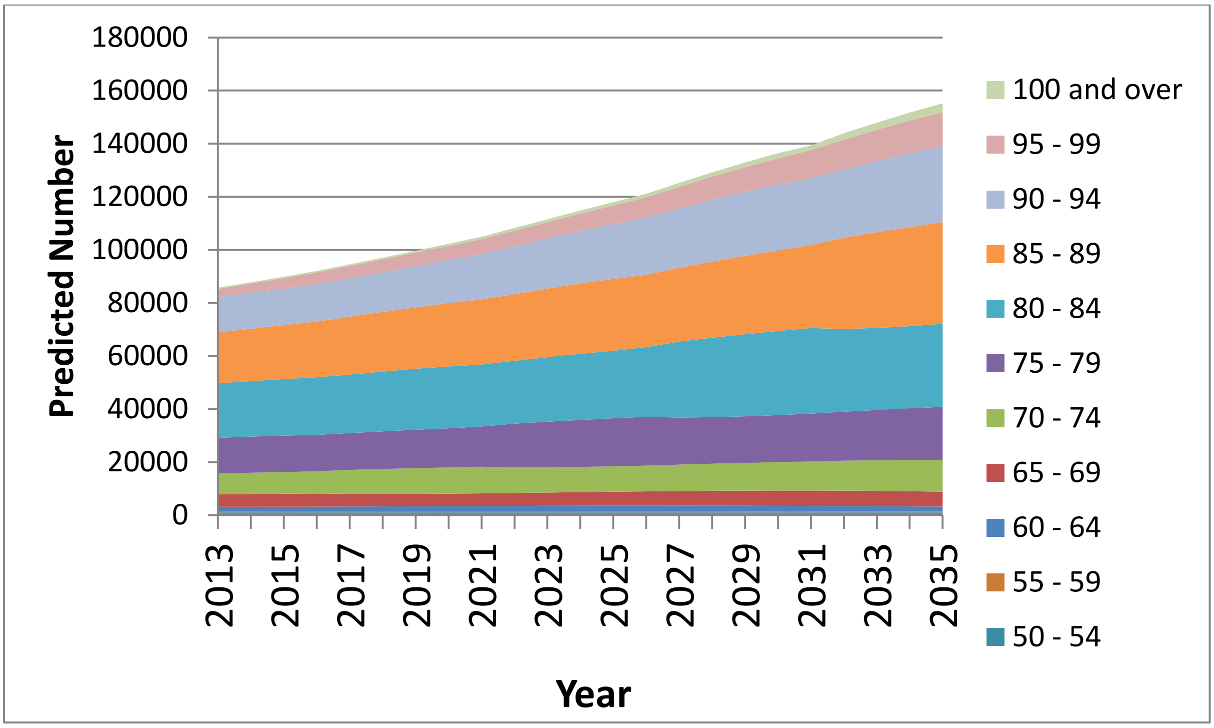
Larson and Langa reviewed the US work(122), and findings from the Rotterdam studies. They conclude that there is reason for cautious optimism that improvements in risk factors may be producing a decrease in age-specific rates. Some countries have modelled the relative impact of different levels of risk factor reduction, and this would be worthy of consideration in Scotland.

Predicted Prevalence at Current Rates

Alzheimer Scotland produced a thorough review of this area in 2007(123). This discussed the most appropriate age-specific prevalence estimates for Scotland. Since then, however, Alzheimer Scotland have moved to use EuroCoDe estimates for people aged 60 years and over(29), and figures from Harvey for people aged under 60 years(124). This means that the estimates in their 2007 report are no longer in line with their current prevalence estimates.

Rather than introduce conflicting estimates, this report uses the age-specific prevalence rates used by Alzheimer Scotland, and applies them to population estimates. Alzheimer Scotland estimate current numbers using five year age bands, including 90–94 years, 95–99 years, and 100 years and over. The 2010 Office for National Statistics based population projections were used (National Population Projections, 2010-Based Projections, Table A3-6, Principal projection - Scotland population single year of age, 2010-based). This was used in preference to the Scottish equivalent table as the Scottish table, based on the ONS table, combines all people of 90 years and over in to one age group.

Figure 2: **Projected Number of People with Dementia in Scotland by Age Group (2013 – 2035)**



As is apparent, the great majority of the projected increase is in people aged 80 years and over. The importance of the true future prevalence is therefore apparent. There is a gearing effect of more people in the very oldest age groups, combined with a higher prevalence in these age groups. A modest reduction in prevalence in age bands can, therefore, result in a markedly different picture.

The youngest people in the 80–84 age band in 2035 will, at present, be in their late fifties. This gives a considerable period of potential intervention. The importance of preparation and incorporation of work on dementia in to routine practice is apparent, as is the potential value of intervention.

Carers in the Future

> *'In recent years, much discussion has taken place about projected increases in the number and proportion of elderly people in the UK population over the coming decades. Forecasts also point towards a decrease in the number of people of working age to each elderly person in the population.'* (125)
>
> *Scottish Executive, 2006*

The Scottish Executive undertook an important review of the modelling literature on future informal caring(125). They note that the relationship between an increasing number of older people, and care demand, is not as straightforward as may be assumed, as it is the prevalence and severity of disability that drives care requirements.

Migration resulting in family dispersion, and therefore greater distances between affected people and potential carers, is important. This is also related to increased population affluence reducing the financial need for older people to reside with family (see Scottish Executive 2006 for a summary of the literature (125)). Similarly, some factors such as a decision to have a family later, which may result in less time available to adult children to look after a parent while also having a young family themselves, may affect the availability of care.

The report reviewed various prediction models. Understandably, all included important assumptions, and modelled a range of scenarios. The general result of most models was to suggest that the importance of informal care would increase still further in the future, although with substantial demands for formal care.

The recognition of the importance of informal carers, the major demands placed on them, and their limited satisfaction with existing services, particularly in relation to respite care, resulted in a new Carers Strategy for Scotland(126). Policy on carers specifically in relation to dementia is summarized in the ‘Policy’ section.

Summary

The largest single influence on the number of people with dementia is the age structure of the population. Current demographic projections indicate that there will be a substantial increase in the number of people with dementia. Some risk factors are decreasing, however, and so the true future number of people with dementia is unknown. Information from some population surveys suggests that the age-specific rate of dementia may be decreasing in some older cohorts. This has to be balanced against the larger number of people in these cohorts, and the future impact of current preventative activities and population lifestyle changes. For planning purposes, current projections are helpful, but they should be regarded as estimates and kept under review as trends become more apparent.

4 Treatment and Care

Cameron Stark and Peter Connelly

There is no one pattern of treatment and care in Scotland. This is related to service configuration, service availability and area type (Penny Curtis, Scottish Government, Personal Communication). Increasing Government guidance on service provision, and local and national monitoring, is likely to increase similarities between areas. In some cases, however, the same standards could be supplied in different ways, for example by use of telehealth for greater GP involvement in diagnosis in sparsely populated rural areas.

The Scottish Intercollegiate Guidelines Network (SIGN) produced recommendations on the management of dementia in 2006(127). The National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence also published guidelines in 2006, updated in 2011 to reflect changes in pharmaceutical treatment recommendations(128).

A brief summary of the SIGN guidelines is presented below. The interested reader is directed to the full report, available on-line at www.sign.ac.uk for details and to www.nice.org.uk for the NICE guideline.

Diagnosis

The Scottish Government's 'Standards for Care for Dementia in Scotland'(129) includes standards on diagnosis.

> ***Scottish Standards***
>
> *'People worried about their memory have timely access to services for assessment, including those who may be seldom heard, e.g. homeless people, black and ethnic minority communities, people in remote areas, people with sensory impairment.'*
>
> {{5688 Scottish Government 2011}} 129 (Page 7)

Screening

The UK National Screening Committee reviewed the evidence for a screening programme for Alzheimer's Disease Dementia, using a report from the Public Health Resource Unit(130). The National Screening Committee concluded that screening should not be offered, as there was not sufficient evidence that it met accepted criteria for screening programmes(131).

Timely Diagnosis

The Standards of Care for Dementia state an 'individual' has the right to a diagnosis. This is based on the Charter of Rights for people with dementia which states that people with dementia have the right to the highest attainable standard of physical and mental health. The ultimate source of this is the UN Convention on the Rights of Persons with Disabilities to which the UK is a signatory. Article 25(b) states that "In particular, States Parties shall: Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons"[1].

A paper by Challis *et al* is sometimes cited as evidence of the value of earlier diagnosis(132). The paper describes a randomised controlled trial in which new referrals to a Community Mental Health Team were randomly allocated to either treatment as usual, or to a CMHT plus case management service. By year two, significantly more people in the case management group had remained at home, compared to the care as usual group (51% compared to 33%). Most of the benefit seemed to accrue in the second year of care. There were significant benefits to carers. The overall cost of the case management group was, however, higher than that of the care as usual group, despite a saving to carers. This was accounted for by increased acute hospital costs, day care costs, professional visits and social service costs. The community service was described by the authors as a 'relative resource rich context' (page 323). This study provides evidence for improved quality of care, but not obviously for the value of earlier diagnosis. Other papers often cited in papers as showing evidence for the value of intervention also appeared to be on related topics, but not to directly address the question of the value of earlier diagnosis.

Professor Martin Prince and colleagues from the Institute of Psychiatry at King's College, London, conducted a review of the evidence for Alzheimer's Disease International(133). They used a systematic review method, which is best practice in seeking to gather published evidence. They looked for evidence of impact on a range of measures, including outcomes for the person, for carers, and for society as a whole.

They concluded:

> *'Despite an extensive search of the scientific literature, we found almost no research conducted into the effect of the timing of dementia diagnosis upon subsequent disease course and outcomes for the person with dementia and their carers. The evidence that we did find is supportive of a possible beneficial effect of earlier help seeking and/or earlier diagnosis and/or earlier intervention upon survival, but this requires confirmation in other studies. The two studies of the effect of disease stage at diagnosis upon subsequent cognitive decline*

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[1] UN Convention on the Rights of Persons with Disabilities.Article 25(b)

http://www.un.org/disabilities/convention/conventionfull.shtml.Accessed 18 July 2013.

> *showed no association, but were too small in size to reach any clear conclusion.' (page 29).*

As with the experience noted above of seeking evidence from published work, Prince and colleagues noted, *'Several of the papers that we reviewed in the course of our systematic review contained statements regarding the benefits of early diagnosis. Many were unreferenced, and where references were provided these were generally to other papers making similar, non-evidence based assertions.'*(133) (page 28). As Prince notes, this does not prove that there is no benefit, but it does mean that the drive towards earlier diagnosis is based on opinions on good practice, and on views on appropriate care values.

Prince et al reviewed the wider literature on the topic, and concluded that there was general support for earlier diagnosis and that this cited nine main reasons(133) (page 30):

- optimising current medical management
- relief gained from better understanding of symptoms
- maximising decision-making autonomy
- access to services
- risk reduction
- planning for the future
- improving clinical outcomes
- avoiding or reducing future costs
- diagnosis as a human right

This argument has been accepted by the Scottish Government and national policy is to promote timely diagnosis wherever possible.

Diagnostic Standards

There are several national standards around diagnosis. There should be clear pathways and availability of specialist services as required.

> ***Scottish Standards***
>
> *GP surgeries and hospitals have established pathways to diagnosis in place. This should include: referral to a service that specialises in the diagnosis of dementia when appropriate, identification of who is best placed to carry out specific roles in relation to diagnosis and pre and post diagnostic support.*
>
> ***NHS Boards will ensure that** GPs and hospitals can refer people with suspected dementia to services that specialise in the diagnosis of dementia. Services will have initial contact with the person within four weeks. Services that specialise in the diagnosis of dementia can refer on to a neurologist, neuropsychiatrist or neuropsychologist if the diagnosis is complex. '*
>
> 129 (Page 7)

The SIGN and NICE guidelines cited above include information on diagnostic processes. They make broadly similar recommendations(127), on the need for a comprehensive assessment, including history taking, cognitive and mental state examination, physical examination and review of medication. This includes consideration of the possibility of depression or delirium.

SIGN makes specific recommendations including:

- In individuals with suspected cognitive impairment, the Mini Mental State Examination (MMSE) should be used in the diagnosis of dementia (the copyright for the MMSE has been enforced, and there is UK wide negotiation underway on access to the MMSE for NHS use).

- Initial cognitive testing can be improved by the use of Addenbrooke's Cognitive Examination. This examination includes the MMSE, and so is also subject to copyright issues. It has been superseded by the ACE3.)

- The Informant Questionnaire on Cognitive Decline in the Elderly (IQCOD) is a short questionnaire filled out by someone who knows the patient and can be an adjunct to direct cognitive testing.

- Physical investigations including laboratory tests should be selected on clinical grounds according to history and clinical circumstances.

- As part of the assessment for suspected dementia, the presence of comorbid depression should be considered.

- Structural imaging should ideally form part of the diagnostic workup of patients with suspected dementia.

- SPECT may be used in combination with CT to aid the differential diagnosis of dementia when the diagnosis is in doubt.

- CSF and EEG examinations are not recommended as routine investigations for dementia.

- Neuropsychological testing should be used in the diagnosis of dementia, especially inpatients where dementia is not clinically obvious.

- It may be useful to repeat neuropsychological testing after six to 12 months in patients where:

    - the diagnosis is unclear
    - measurement of the progression of deficits in a typical pattern supports a diagnosis of dementia and helps in differential diagnosis.

The more recent NICE Guidelines recommend the use of a standardised instrument to assess cognition, but are not prescriptive about choice of instrument(128).

Imaging is recommended in order to exclude other pathology, and to help to identify dementia sub-type.

The Scottish Government focus on Integrated Care Pathways for dementia(134) offers an opportunity to agree processes in each area and to make them clear to everyone.

Community Services for People with Dementia

> *'An estimated 44% of people with dementia live at home and require care at least once a day; 13% live alone and a further 30% live with family. People living alone need support and stimulation to remain independent for as long as possible, whilst those living with family require community care services to maintain and support the caring relationship.'*(135)(page. 5)

Alzheimer Scotland undertook a survey of community services for people with dementia(135). They pointed out that the purpose of community services was not only to provide care, but also to help maintain skills in the affected person. They concluded that, too often, staff were under pressure to move on to the next client, and focused on tasks, rather than on work with the person that would help them to continue to do things themselves.

There is no reliable information on what proportion of people require care of different intensities. Alzheimer Scotland used figures from Melzer and colleagues, which were in turn adapted from earlier work(135). This estimated that 6% of people with dementia need no care; 11% need care weekly; 48% need some type of care daily; and 34% need constant care or supervision. The final figure concords reasonably well with estimates of the proportion of people in care homes.

It seemed very likely from the information received from local authorities that there were waiting lists for some types of care, and a short fall in the proportion of people who were able to receive care. There are, clearly, assumptions and approximations in this estimate, but the there was no other obvious way to undertake the assessment, and the Alzheimer Scotland report does give useful information on which to base future reviews. The report felt there was a focus on traditional models of service delivery and insufficient attention to what might now be referred to as skills maintenance and re-ablement models.

Respite care, in particular, tended to be delivered exclusively in care homes. Respite care was seen as particularly important by many carers, a finding echoed in the later summary of the views of users and carers. There is limited evidence that this affects overall outcomes (e.g. movement to institutional care)(136,137). Services tended to be offered in office hours, and on weekdays, which did not always reflect the needs of younger carers with other demands on their time. The needs of younger people with dementia, and of men with dementia, did not always appear to be recognised and met.

People with Dementia in Care Homes

As noted earlier in the report, a large number of people with dementia are in care homes, and a high proportion of care home residents have dementia.

Decisions on admission to care homes are difficult for the person and their family, and careful support can be required. Alzheimer Scotland publish information and guidance for relatives(138,139).

Work by the Care Quality Commission in England found that, in many areas, people with dementia were more likely to be admitted to hospital with avoidable conditions than people who did not have dementia(140).

Alzheimer Scotland produced a valuable report on care homes in 2005(141,141). This detailed report noted that, in the years since a previous review in 1996, there had been a substantial move from hospital care to care home residence for people with dementia. They estimated that almost a third of people with dementia in Scotland lived in a care home.

They noted that the Care Commission reported that the highest proportion of upheld complaints were in homes for older people(142). The Alzheimer Scotland report commented (page7):

> *'There is still a great variability in the quality of care in care homes across Scotland; only a small percentage of care home staff have been trained in dementia; the staff-to-resident ratio is still not high enough; and the inappropriate prescribing of antipsychotic drugs continues.'*

While there were examples of good practice, the report raised considerable concerns about person centred care (with very little non-procedural interpersonal care), and the knowledge and experience of staff, and the NHS and social care systems that were in place to support them.

Many of these issues are specifically addressed by current Scottish policy, but it is clear that the transition to care home care, and the quality of that care, is a crucial component of overall service quality for people with dementia. Carers may continue to need support after their relative is admitted to a care home(143,144). Issues such as therapeutic activities respect for the wishes of the person with dementia, involvement of relatives and carers, and ability to cope with challenging behaviours are all extremely important. End of life care is also important, and there is reasonable evidence that it can be improved. (145)

People with Dementia in General Hospitals

> *'Acute services are geared towards fast and effective responses, assessment, diagnosis, intervention, cure, if possible, and discharge….Care is based on an assumption that patients will be able to express their wishes, acknowledge the needs of other patients, move through the system as required, have their acute needs addressed and be discharged home or to other services….a person with a dementia may be unable to comply in many of these areas. Small*

> *considerations in how care is delivered can help to create a more positive hospital experience for individuals, such as making the environment as trauma free as possible, trying to preserve continuity with what is familiar to the individual, taking time to reassure, and giving information and support in ways appropriate to the individual.'*(146) (page 3)

As noted in the policy section, the care of people with dementia in general hospitals is a particular priority for the Scottish Government(129,134,147). In a systematic review by Mukadam and Sampson, people with dementia who were admitted to general hospitals were more likely than other people to have a low Body Mass Index and poorer nutritional status at the time of admission, to have a significantly longer length of stay than other patients, and to have poorer outcomes (148). People with dementia were often admitted from institutional care and frequently had infective diseases.

Sheehan and colleagues reviewed the literature on general hospital admissions for people with dementia and concluded(149):

- Half of people with moderate dementia admitted with acute illness such as hip fracture or pneumonia will die within 6 months
- Dementia increases the risk of institutionalization and mortality after hospital admission
- People with dementia are at high risk of developing major complications of illness such as pressure sores, falls and incontinence
- Patients with dementia are less likely to be referred to palliative care, less likely to receive palliative medication, and less likely to receive specific medical interventions

In the Care Quality Commission review of general hospital admissions in England mentioned above, in almost a third of instances, the acute hospital had no record in their notes that the person had dementia(140). This was more frequent in elective admissions than in emergency admissions. People with dementia tended to stay in hospital significantly longer than people without dementia, for both elective and emergency admissions. In both elective and emergency admissions, people with dementia had higher death rates. The differences were largest in elective admissions, where readmission rates were also increased.

The Mental Welfare Commission suggests that up to a quarter of all Scottish hospital beds are occupied by people with dementia aged over 65 years at any one time (150). They comment:

> *'When admitted to hospital, people with dementia can experience increased levels of confusion and loss of their abilities and, where possible, alternatives to admission should always be explored. On average, people with dementia stay longer in hospital than other people who are admitted for the same medical procedure.' (page 2)*

The Mental Welfare Commission found little evidence that admissions could have been prevented at the time of admission, but they suggested that earlier intervention might have reduced the risk of admission in some instances. They found that information had not always been obtained from relatives, and they pointed out that this made it difficult to distinguish between delirium and dementia. The importance of identifying delirium has been emphasised in other settings and Scottish guidance is available(151).

Other issues identified by the Mental Welfare Commission included a lack of knowledge on the legal requirements around consent to treatment, including the use of covert medication and psychoactive drugs; access to specialist mental health advice; encouraging a presumption that people should return to their own home if at all possible, and ensuring an appropriate environment.

DEMENTIA-FRIENDLY DESIGN STANDARDS

'The Stirling Standards for dementia-friendly design reflect the need for people with dementia to feel calm, relaxed and safe within an environment which is easy to navigate and provides purpose. Design features must promote best practices and enable people with dementia to live well. The Stirling Standards for dementia-friendly design can be accessed at the Dementia Services Development Centre website.'

Suzanne Croy
Dementia Lead Associate, Dementia Services Development Centre

Over half of all new admissions to care homes in the UK are from general hospitals(152). Sheehan and colleagues provide a useful summary of the literature on general hospital care(149).

Stewart et al suggest(153):

- More open involvement and communication with families
- Explanation that legally it is appropriate to take certain risks
- An effective advocacy service for people with dementia
- More frequent assessment of capacity/best interests in the discharge planning process
- The increased use of trial home discharges

Sheehan notes that there are significant challenges in following such recommendations in general hospitals with enormous operational pressures(149). They point out, however, that many older people have cognitive impairment at the time of admission that improves before discharge, and that further improvements are common after discharge, suggesting that initial assessments should be revisited.

Non-Pharmaceutical Interventions

Care Planning

The NICE and SIGN guidelines both emphasise the importance of care planning. NICE comments:

> *'Health and social care staff should aim to promote and maintain the independence, including mobility, of people with dementia. Care plans should address activities of daily living (ADLs) that maximise independent activity, enhance function, adapt and develop skills, and minimise the need for support. When writing care plans, the varying needs of people with different types of dementia should be addressed. Care plans should always include:*

- *consistent and stable staffing*
- *retaining a familiar environment*
- *minimising relocations*
- *flexibility to accommodate fluctuating abilities*
- *assessment and care-planning advice regarding ADLs, and ADL skill training from an occupational therapist*
- *assessment and care-planning advice about independent toileting skills; if incontinence occurs all possible causes should be assessed and relevant treatments tried before concluding that it is permanent*
- *environmental modifications to aid independent functioning, including assistive technology, with advice from an occupational therapist and/or clinical psychologist*
- *physical exercise, with assessment and advice from a physiotherapist when needed*
- *support for people to go at their own pace and participate in activities they enjoy.'* (page 29)

Much of the evidence on interventions is relevant across health and social care settings, particularly in relation to non-pharmacological interventions.

Cognitive Symptoms and Maintenance of Functioning

NICE(128) and SIGN(127) both agree that structured group Cognitive Stimulation Therapy should be offered to people with mild to moderate dementia of all types.

Non-Cognitive Symptoms and Behaviours that Challenge

While slightly different terms are used by the two groups, and NICE had access to more recent evidence, there is general agreement in the two sets of recommendations.

A thorough assessment is needed when people's behaviour changes, or begins to challenge services. NICE comment:

> *'For people with all types and severities of dementia who have comorbid agitation, consideration should be given to providing access to interventions*

> *tailored to the person’s preferences, skills and abilities. Because people may respond better to one treatment than another, the response to each modality should be monitored and the care plan adapted accordingly. Approaches that may be considered, depending on availability, include aromatherapy, multisensory stimulation, therapeutic use of music and/or dancing, animal-assisted therapy and massage.*
>
> *These interventions may be delivered by a range of health and social care staff and volunteers, with appropriate training and supervision. The voluntary sector has a particular role to play in delivering these approaches. Health and social care staff in the NHS and social care, including care homes, should work together to ensure that some of these options are available, because there is some evidence of their clinical effectiveness. More research is needed into their cost effectiveness.’* (page 34)

This identifies a tension between provision of what might be useful to an individual, and the cost of provision, particularly when there is little understanding on which individual will benefit from a specific intervention. Pragmatic arrangements in local areas to make relevant treatment modalities available will be required. The SIGN report makes the point that endorsement of a treatment does not mean that it is appropriate in all instances. For example, multisensory approaches are not recommended for the relief of neuropsychiatric symptoms in people with moderate to severe dementia (page 10).

Pharmaceutical Interventions

Scottish Standards

‘Assessment for the use of nationally recognised and approved drug treatments for dementia is carried out using an approved assessment tool and approved treatment prescribed and reviewed where clinically indicated.’

129 (Page 24)

There are two main categories of drugs that offer some treatment benefits. A recent NICE review(154) was accepted by Health Improvement Scotland, and supplements previous Scottish Medicines Consortium and SIGN advice.

Three cholinesterase inhibitors (donepezil, rivastigmine and galantamine) have been accepted by NICE as being effective in mild and moderate Alzheimer’s Disease Dementia. Memantine, which works by blocking glutamate, has been approved for severe Alzheimer’s Disease Dementia, and for moderate dementia where the person cannot tolerate a cholinesterase inhibitor. Severity is based on MMSE scores, combined with clinical judgement, taking in to account situations in which routine rating scales may not be appropriate (e.g. language problems, learning disability).

NICE concluded that there was no evidence that any of the drugs affected the course of the disease. There was no evidence to support combination treatment with the two classes of drug. The treatment benefits of the cholinesterase inhibitors were ‘small but demonstrable’ (154)(page 74), and the cost was justified mainly by a delay in admission to institutional care (of between 1.4 and 1.7 months). Some observational evidence does suggest delays in admission to institutional care in the USA associated with drug treatment(155), but no comparable UK reports were identified.

NICE concluded that there was no persuasive evidence that any of the three cholinesterase inhibitors was more effective than the others, and therefore recommended that choice be based on cost, unless there was a specific clinical reason for choosing another drug.

In economic modelling of memantine, admission to an institution was delayed for around a month (page 44). NICE modelling of cost effectiveness produced different results from the manufacturer’s model, mainly because the manufacturer predicted a slightly longer delay in the move to institutional care, and cessation of prescription on admission to an institution (which was not assumed in the NICE model).

The NICE guidance recommends:

> ‘*Treatment should be continued only when it is considered to be having a worthwhile effect on cognitive, global, functional or behavioural symptoms.*
>
> *Patients who continue on treatment should be reviewed regularly using cognitive, global, functional and behavioural assessment. Treatment should be reviewed by an appropriate specialist team, unless there are locally agreed protocols for shared care. Carers’ views on the patient’s condition at follow-up should be sought*.’(154) (page 4–5)

Healthcare Improvement Scotland reviewed this guidance and stated(156):

> *‘NHS Scotland should note that:*
>
> *No important differences were identified for this NICE appraisal and NHS Quality Improvement Scotland advises that the recommendations are as valid for Scotland as for England and Wales.*
>
> *However, in line with existing practice in Scotland, when access to a specialist is not possible, or may be unacceptably delayed due to local circumstances, diagnosis may be made by a general practitioner who has substantial experience in the diagnosis of dementia.*
>
> *In cases where clinical diagnosis is judged to be straightforward, treatment may be initiated and re-assessed by the experienced general practitioner according to a shared-care protocol which should include telephone consultation with a specialist and clear treatment end points.’*

Anti-Psychotic Drugs

Banerjee summarises the evidence on the use of antipsychotic drugs in people with dementia(157). These drugs are often used to control behavioural symptoms, such as agitation, aggression, wandering, shouting and psychotic symptoms. There is limited evidence of their effectiveness, and adverse effects are frequent. Banerjee estimates that if 1,000 people with dementia are treated with antipsychotic drugs for twelve weeks, then there would an additional 18 strokes, ten deaths and almost 70 people with problems with their walking(157). These figures are based on extrapolation from trial evidence from acute treatment, and it is not clear if the same rate of adverse effects is associated with longer treatment. The challenge for clinicians is that behavioural problems reduce quality of life for people with dementia, and this has to be balanced against treatment risks.

The NHS Institute for Innovation and Improvement commissioned a health economics analysis of non-pharmacological alternatives to anti-psychotic drug use. The researchers concluded that behavioural interventions were more expensive than anti-psychotic drug use, but generated considerable NHS savings. The authors estimated that, for every £1 spent on behavioural interventions, there would be £1.99 of health care cost savings and quality of life gains. Most of this gain came on prevention of stroke and was, therefore, largely opportunity costs(158).

Support for Carers

It is clear that carers play a vital role in the care of many people with dementia and make an enormous contribution to overall care provision.

Both SIGN and NICE make clear recommendations about the importance of support for carers(127,128). The Scottish Charter(159) and the National Standards both make explicit mention of support for carers(129). SIGN point out that support for carers, as well as being morally important, may increase the time a person spends at home(127).

The commitment to having a clear route of appropriate support in the year after diagnosis is partly aimed at meeting this requirement, but a range of approaches are required to fit the needs and timing of different families. NICE point out that support can include education, peer support, various types of respite / short breaks, and psychological support (128).

Services in Rural Areas

Delivering services in rural areas has substantial challenges. People with dementia and their families may be far from centres of service provision, including out-patient clinics, hospitals, day hospitals and care homes(160)(161). Community support is often good, but it is not practical to rely on community or family support alone(162). It can be difficult for services to provide dementia day care, home support, and it may be difficult to identify appropriate support even with Self-Directed Payments (163). While some service users and their families report positive experiences with services, others describe difficulties over communication and liaison(164). Specific consideration of the balance of services, and attention to transport difficulties (including wheelchair accessible transport) and care availability, is likely to be required.

Palliative Care

Progressive dementias invariably lead to death. NICE promotes careful consideration of palliative care needs in people with dementia, including appropriate use of pain relief and good communication within care teams on a person's palliative care requirements. NICE provide a helpful discussion of artificial feeding, decisions to resuscitate and approaches to end of life care(128).

Summary

The Scottish Government promotes timely diagnosis of dementia. Diagnosis needs to be readily available, and efficiently conducted. Standards on diagnosis are available and are supported by the Scottish Government's guarantee on post-diagnostic support. Many people with dementia live at home, and community services have to be appropriate to their needs.

People with dementia can benefit from pharmaceutical interventions and from psychological interventions such as Cognitive Stimulation Therapy. Access to non-pharmacological treatments is patchy at present. Human interventions of various types, such as carer support and CST are vital forms of therapeutic intervention in dementia.

Many people with dementia have to be admitted to general hospitals. Older people are part of the core business of general hospitals and people with dementia are an important sub-group, who need excellent care that is adapted to their needs. Ensuring that general hospitals recognise people dementia, and offer them appropriate care to the affected person is an important aim of current Scottish policy.

Care homes are also an important site of care delivery. While some care is excellent, reports suggest that, as with general hospitals, care does not always meet people's needs, and can involve little care that is not directly related to a physical need.

Family and carers play a key role in dementia care and deliver a very large volume of non-statutory care. Providing appropriate information and support is important. Carers often find the transition of their loved one to institutional care difficult, and support may also be needed at this point in the care journey.

How all this is to be addressed is considered in the next chapter dealing with dementia policy in Scotland.

5 Scottish Policy on Dementia

> *'This strategy is about getting dementia care right. It is about advancing a reform agenda rather than rolling out a big programme of investment. The reality is that the strategy will be taken forward amidst the most stringent spending cuts for a generation.'*
> Councillor Ronnie McColl, COSLA Spokesperson on Health and Wellbeing(134)

The National Dementia Strategy

There are a series of key documents on Scottish dementia policy, beginning with the 2010 National Dementia Strategy(134). The strategy was underpinned by principles developed in Scottish Parliamentary Cross-Party Group on Dementia's Charter of Rights for People with Dementia and their Carers(159). The strategy identifies key challenges, two priority delivery areas, and a series of actions.

The 2010 strategy estimates the economic cost of dementia, based on work by Alzheimer Scotland, at about £1.7 billion, of which £6–700 million was direct health and social care costs(page 13). The strategy emphasises the large expected increase in the number of people with dementia, and the importance of improving responses. It notes that in Scotland:

- significant resources are already invested in dementia care;
- most of the resource is directed at high-cost, long-term settings;
- there is limited post-diagnostic support;
- preventative support may not be available to help prevent or reduce problems, because of resource constraints and competing demands; and
- services are often 'one size fits all' – the report notes, '*What is often needed is better support for a person's existing system of care rather than something that will replace it'* (134)(page 21).

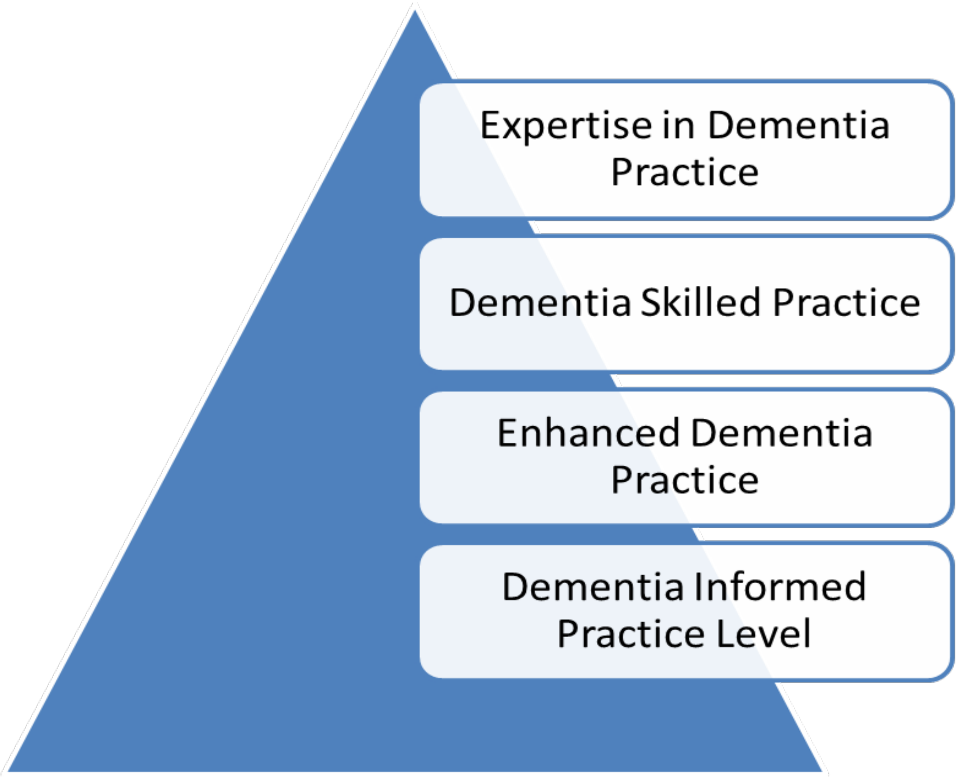
As noted in Table 1, action was promised on a range of supporting work, including the development of care standards, implementation of dementia care pathways; production of a skills framework for people supporting people with dementia and their families, and work to improve information.

Knowledge and Skills Framework

'Promoting Excellence' provides a framework which sets out the knowledge, skills, and behaviours expected of health and social care staff(165). The report makes it clear that it intended to apply to all staff, and that is deliberately challenging, rather than a description of current practice.

The 'Dementia Informed Practice' level is required of all health and social care staff. 'Enhanced Dementia Practice' is intended for staff with direct and / or substantial contact with people with dementia, while 'Dementia Skilled Practice' is expected of staff who have regular and / or intense contact, manage relevant services, or deliver interventions. The 'Expertise in Dementia Practice' level is for staff who have an expert, specialist role. Each level incorporates the skills of the previous level, in a tiered hierarchy.

Figure 3: Levels of Training in Health and Social Care Staff



Source: Adapted from (165)

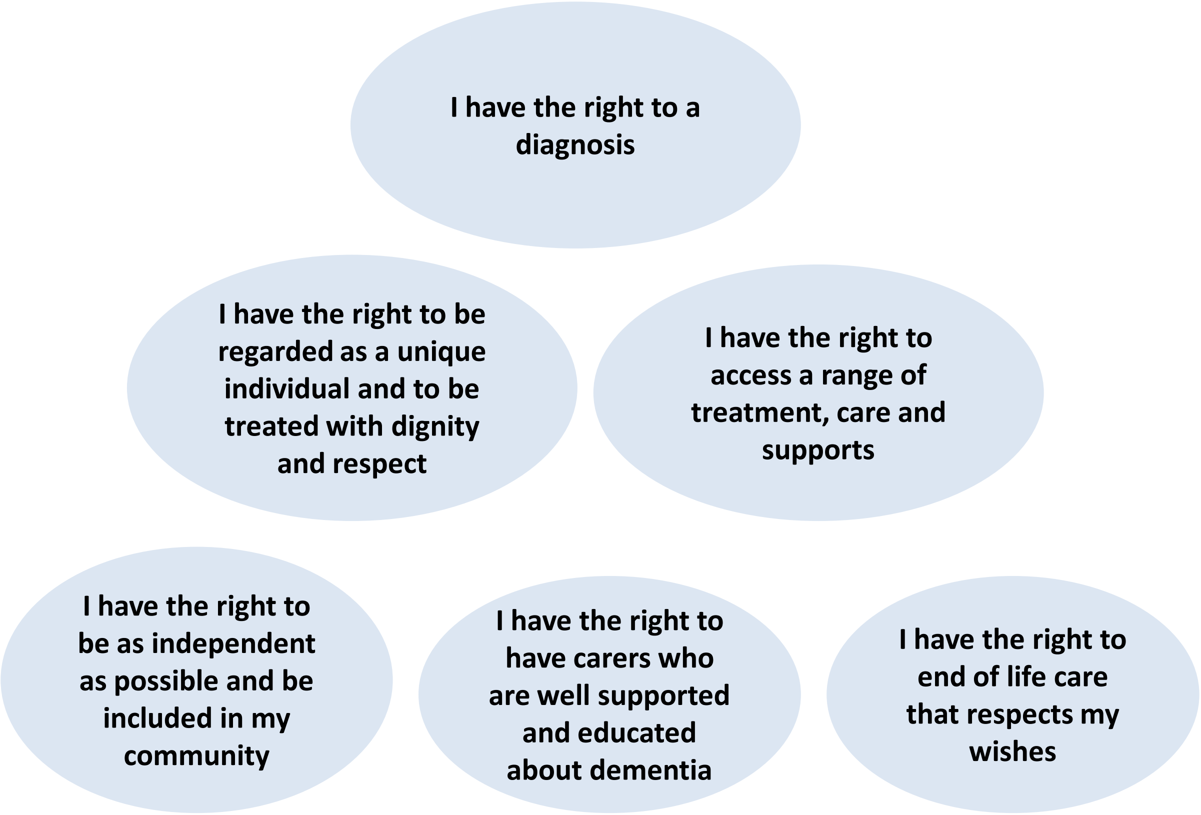
The knowledge and skills for each level of practice are described, and linked to the requisite standard in the national dementia standards document(129).

Dementia Standards

The Scottish Government's dementia standards(129) are based on the Charter of Rights(159) and link to the national strategy(134). The Knowledge and Skills Framework refers directly to the standards(165).

The six standards are shown in Figure 4. In the standards document(129), each standard is linked to the Charter of Rights(159), and detailed examples of requirements that flow from the standards are provided.

Figure 4: National Dementia Standards



I have the right to a diagnosis

I have the right to be regarded as a unique individual and to be treated with dignity and respect

I have the right to access a range of treatment, care and supports

I have the right to be as independent as possible and be included in my community

I have the right to have carers who are well supported and educated about dementia

I have the right to end of life care that respects my wishes

Source: (129) (page 5)

These standards then produce a list of required actions. The strategy also identifies the type of evidence that can be used to demonstrate that a standard is being met.

For example, ‘I have the right to access a range of treatment, care and supports’, is then divided into:

- Have access to independent advocacy services.
- Be able to easily obtain information and advice about supports and care services that are available locally in order to make informed choices.
- Receive a good quality, timely and integrated assessment.
- Experience a person-centred approach to support and care.
- Receive treatment that is in line with the law.
- Receive treatment that is likely to be of benefit, including a range of non-drug based treatments.
- Receive good quality care if admitted to a general hospital, accident and emergency department, or attend an out–patient department.

These then identify specific duties of relevant organisations.

Since then, a new HEAT target has been introduced. ‘Everyone newly diagnosed with dementia will be entitled to at least a year’s worth of post-diagnostic support, coordinated by a named link worker'(147). This builds on the rights in the Charter (159).

Dementia Integrated Care Pathway

The dementia Integrated Care Pathway (ICP) is envisaged as one of the methods by which care quality can be improved, and some of the standards delivered.

There are three types of ICP standards relevant to dementia(166):

- Generic care standards: describe the interactions and interventions that must be offered to all people who access mental health services.
- Condition-specific care standards: build on the generic care standards and describe the interactions and interventions that must be offered by mental health services to people with a specific condition.
- Service improvement standards: measure how ICPs are implemented and how variations from planned care are recorded and acted on.

Dementia is one of a number of condition-specific pathways (Figure 5).

Figure 5: Mental Health Integrated Care Pathways

Source: Healthcare Improvement Scotland

While the generic mental health care standards are as relevant to dementia as to any other condition, the requirements specific to dementia include:

- The care record shows that a treatment algorithm for cognitive impairment based on current national recommendations is followed.
- The care record shows that an appropriate assessment tool has been used to evaluate treatment outcome.
- The care record shows that service users who develop behavioural or psychological dementia symptoms have a review of their care plan within 4 weeks.
- There is a local system in place for a structured and systematic response to the development of behavioural or psychological dementia symptoms.
- The care record shows that an appropriate assessment tool has been used to assess the efficacy of medication.
- The care record shows advance planning in relation to end of life care, which is:
    - reviewed at least annually.
    - includes consideration of the preferred place of treatment if the condition worsens.

The links to the national Dementia Strategy are clear, and provide health care specific requirements that fit well with the structure used in the strategy.

General Hospitals

> *'It is estimated that people with dementia over 65 years of age are currently occupying up to 25% of hospital beds at any time. In Scotland, up to 30% of all people admitted to medical wards are described as having significant memory problems but, of this group, only 30% will have a diagnosis of dementia. Many older people admitted to general hospital will have symptoms but no formal diagnosis of dementia.'*
> Mental Welfare Commission for Scotland(150) (page 2)

The care of people with dementia in general hospitals has attracted considerable attention. The Mental Welfare Commission for Scotland (MWC) conducted a series of visits to general hospitals(150). While care was often good, they made several observations:

- Although few admissions could have been prevented at the point of referral, they felt some admissions could have been prevented by more responsive community services for people with dementia and their carers.
- Moves between wards were minimised and staff paid attention to nutrition. Screening tests were used, but as relatives and carers were not always involved, the MWC felt that it could be difficult to distinguish between delirium and dementia.
- Legal safeguards were not always applied, and specialist advice on the use of psychoactive medication was not always obtained. Guidelines on covert administration of medication, and on making decisions not to resuscitate, were not always followed.
- General hospital staff needed to be more aware of Incapacity Legislation and Human Rights Act requirements.

- Wards needed to be more ‘dementia friendly’, given the high number of people with dementia on them. The MWC recommended that service managers and infection control staff discussed the balance of risk with one another.
- Aiming for return to home, rather than a move to a care home, should always be the starting point, they felt.
- There needed to be good access to specialist advice.

Particular issues of note included:

> ‘According to the ombudsman *“It is unacceptable for health practitioners not to show proper understanding of the legislation and policies that exist to ensure that patient’s human rights are not breached.” Unfortunately, it appears to us that very few practitioners correctly applied the law on medical treatment for adults with incapacity’.* (page 14)

Another key issue was anti-psychotic prescribing. Lack of documentation was, in some cases, combined with a lack of assessment of ability to consent to medication.

The Scottish Government continues to identify work in general hospitals as an important priority(167), and work to deliver the required standards is being led by the Chief Nursing Officer.

Anti-Psychotic Prescribing

Guthrie and Clark provide a valuable review of prescribing of anti-psychotic drugs for people with dementia(168). They note:

- In March 2004, olanzapine and risperidone were found to increase the risk of stroke in people with dementia, and to increase overall mortality rates.
- Typical antipsychotics have been shown to have similar effects, and in 2008 the European Medicines Agency concluded that a class effect was likely.
- In 2009, the UK Medicines Healthcare products Regulatory Agency advised UK prescribers that risperidone was the only antipsychotic licensed for prescription in dementia, for the short-term (less than six weeks) treatment of severe aggression in Alzheimer’s disease.

They reviewed information from 87 Scottish general practices, and concluded that there had been a modest year-on-year decrease in anti-psychotic prescribing between 2003 and 2011.

- 13.5% of old older people with dementia were being prescribed an anti-psychotic drug in the first quarter of 2011
- 83.4% of current users had been receiving the prescription for more than six weeks
- 63.5% of current users had been receiving the prescription for more than 26 weeks
- 6.9% were being prescribed a hypnotic
- 8% were being prescribed an anxiolytic

- 37.1% were being prescribed an antidepressant

The researchers thought that the pattern of anti-depressant prescribing was consistent with the prescription often being for, or also for, agitation. Overall, 48% of people with dementia were being prescribed a psychoactive drug by the end of the period, compared to 38% in 2001.

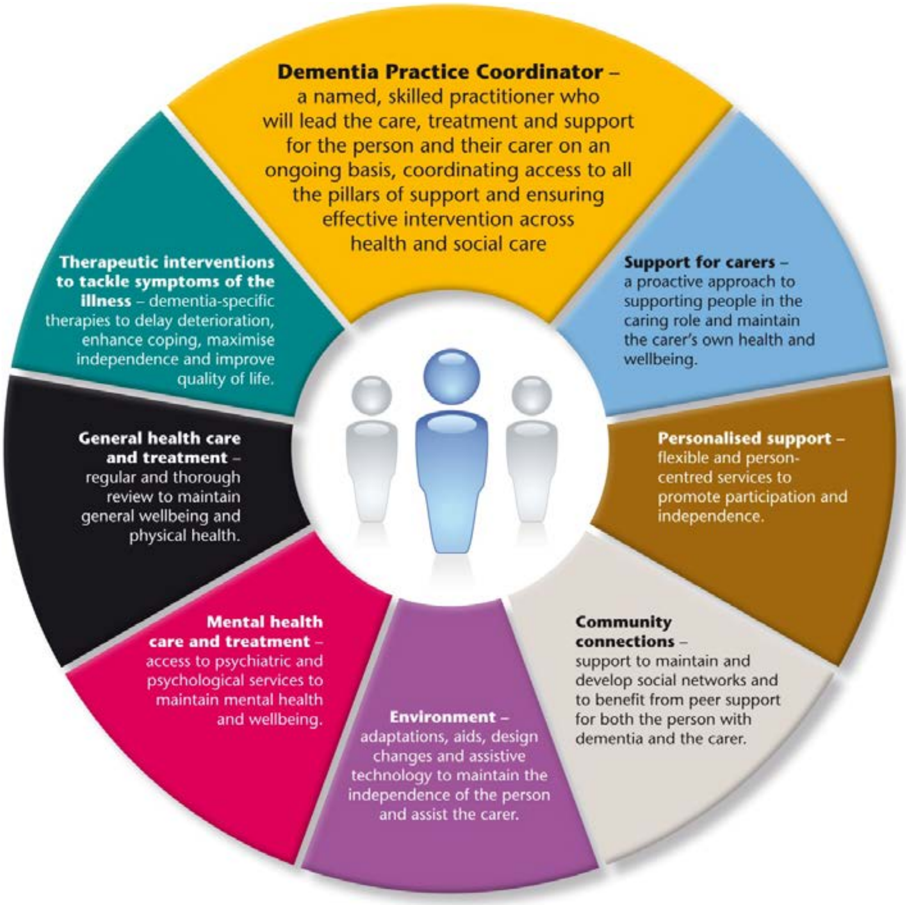
As will be noted below, work on antipsychotic drug prescribing is one of the commitments of the Government strategy for 2013–16.

The Eight Pillars Model

In 2012, Alzheimer Scotland published ‘Delivering Integrated Dementia Care: The 8 Pillars Model of Community Support’(169). This is intended to provide a way in which to develop a coordinated approach to supporting people with dementia and their carers. Alzheimer Scotland present the model as a blue print for integrated dementia care, within the context of health and social care integration, which makes more effective use of existing resources. The components of the model are shown in Figure 6.

The 8 Pillar model builds upon the progress of the national dementia strategy and compliments the 5 Pillars of Post Diagnostic Support which forms of the HEAT target.

Figure 6: The Eight Pillars Model and its relationship to the Five Pillars Model



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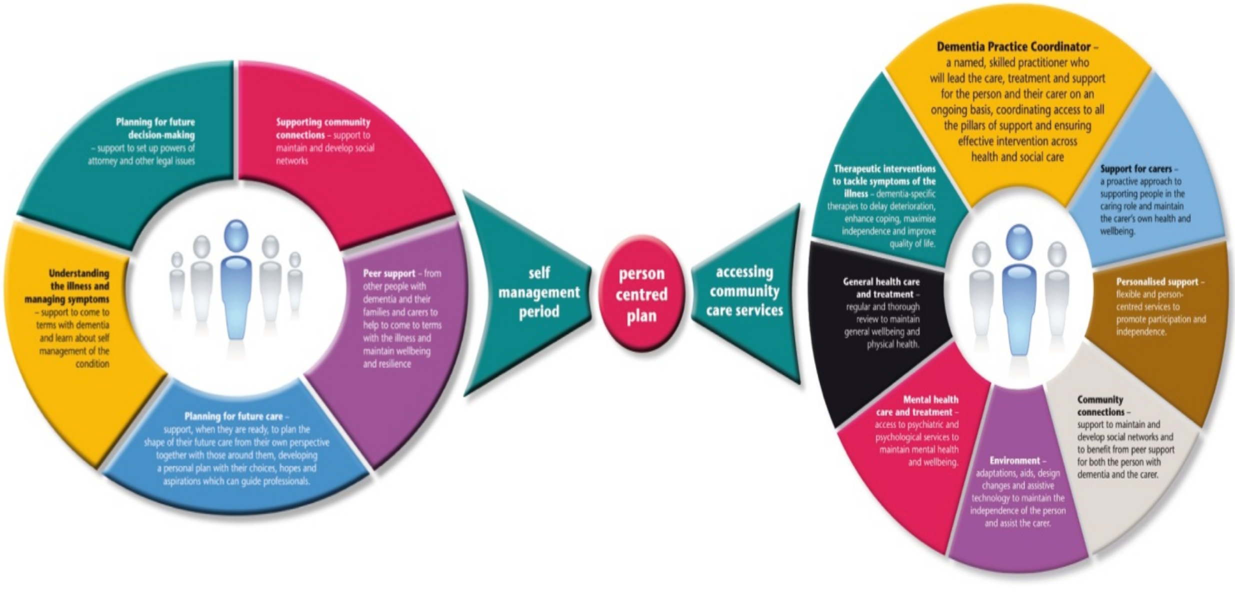

© Alzheimer Scotland 2013

Source: Alzheimer Scotland

This provides a useful way of thinking about the key interventions required to support people with dementia and their carers.

Future Strategic Developments

In developing the strategy for 2013–16, the Scottish Government produced a proposition paper, which set out likely themes(147). These were:

- continuing to focus on promoting and supporting early, accurate diagnosis of dementia;
- supporting a significant improvement in the quality and consistency of post-diagnostic support;
- engaging and involving people with dementia and their families and carers as equal partners in care throughout the journey of the illness;
- supporting people to live a good quality of life at home for as long as possible**,** as they move from self- management to needing more intensive community-based support;
- ensuring people get safe, appropriate and dignified care in hospital and in care homes on every occasion; and
- nurturing dementia-enabled and dementia-friendly local communities.

None of these were new themes. The proposition paper also identified priorities, most of these being continued from previous work, including work on general hospitals, on anti-psychotic prescribing, prevention, diagnosis, and post-diagnostic support. New ideas included a digital hub to provide information for affected people and families, and a programme of work on care homes. The paper also suggested piloting the 'Eight Pillars' model, described above, in the delivery of intensive support. It also saw care standards being aligned with integrated care outcome measures.

The final strategy was published in June 2013, building on the proposition paper, it set out the 17 new national commitments to create an important focus for delivering change over the next three years. The new strategy is available on the Scottish Government website at: http://www.scotland.gov.uk/Topics/Health/Services/Mental-Health/Dementia/DementiaStrategy1316

Summary

Scottish strategy on dementia is well developed. From the Scottish Parliamentary Cross-Party Group on Dementia's Charter of Rights for People with Dementia and their Carers(159), to the recently published strategy, there has been widespread agreement on the main principles. Since the first action plan, a Knowledge and Skills Framework has been developed, and national standards produced. This has been accompanied the introduction of a HEAT target for post diagnostic support based on Alzheimer Scotland's five pillars model. The publication of revised strategy sets out the requirements for further change which is in line with the previous cross-sector agreement on the direction of the work. Local areas are free to consider how to apply the principles, but the national documents provide a thoughtful and agreed framework within which to develop services.

6 Views of the Public, Service Users and Carers

Cameron Stark and Maxine Johnston

Background

There have been several rounds of consultation related to the development of the National Dementia Strategy. There has been other national work, and many examples of local work on public views, including work in rural areas. This section summarises some of the main themes that have arisen in consultations. It is not possible to include all of the wide array of consultations that have taken place in local areas, such as work for Community Care Plans, so this summary focuses on national documents.

National Dementia Strategy Consultation 2010

A series of workshops were conducted to support the development of the national strategy. The report on the five meetings conducted in 2010 divides responses in to General Themes; the Dementia Journey, and General Hospital Care and Treatment(170). The workshops were presented with a report from the work over the previous year, which is summarised below.

General Themes

Promotion and protection of the rights and dignity of people with dementia: There were a series of recommendations on this topic, including the need to promote awareness of the Charter(159), and to promote and monitor compliance using a Human Rights-based approach.

Recognition of central role of carers and families of those with dementia in all settings: at home, in long-term care and in general hospitals: The importance of recognising the essential role of carers and families, and of supporting them.

Personalisation of care at home, in long-term care and in general hospital: Very consistent views across workshops on the importance of personalising care. There was a strong feeling that this should include social inclusion, putting the person and their needs at the centre of their own care, and respecting preferences on end of life care.

Workforce learning, training and development: Staff need to be appropriately trained, and to have access to good quality training and support. Reflected in the later training strategy(165).

Continued focus on research into all forms of dementia; and other dimensions of care such as the experiences and motivations of care-givers: Reflected in the support for Scottish Dementia Clinical Research Network.

The Dementia Journey

Encourage healthy lifestyle choices to reduce the risk of developing dementia in later life: This reflects the discussion in the ‘Risk Factors’ section, and is one of the possible themes for the 2013–2016 national strategy.

Ensure health, social care and voluntary sector professionals are aware of risk and protective factors related to dementia and encourage meaningful and personalised brief interventions: This refers to encouraging actions to reduce future risk, with specific mention of action in minority groups.

Reduce the stigma associated with dementia among the general public and health, social care and voluntary sector professionals: Participants suggested a range of related measures, similar to those undertaken for general mental health issues, and for suicide, through ‘See Me’ and ‘Choose Life’.

Ensure equal access to services: Marginalised groups, including older people living alone, should have equal access to services, and to information.

Assessment, Diagnosis and Patient Pathways: There were a wide range of issues raised here, including good, well-signposted and easily accessible diagnostic services, services which reflected personal choice, and good availability of community services.

Post-diagnostic support in areas such as financial and lifestyle planning: This included issues around peer support, and skills, training and awareness in community support organisations.

Develop community initiatives that are dementia friendly, promote inclusion and reflect the diversity of Scotland’s population: Organisations need to be better able to support people with dementia, and people with dementia should continue to be involved in their community.

Co-morbid conditions: People with dementia have a right to have their physical conditions managed appropriately, and people treating other conditions should have a good knowledge of dementia. This is included in the later skills framework.

Managing and treating behaviour which challenges, and long term care: This dealt with a large number of issues, including; staff training and support; person centred care; availability of therapies and interventions, in line with national guidelines; appropriate prescribing, and much better understanding of legal requirements around consent and the application of Human Rights legislation.

End of life care: Good quality end of life care, including the ability to respect personal wishes.

General Hospital Care and Treatment

Before Hospital: people with dementia should have this diagnosed and the information should be recorded in their medical records: This reflected a general wish to increase the diagnosis of dementia, and to have good access to diagnosis from specific places, such as Parkinson's Disease clinics.

Appropriate information is supplied when a person with dementia is referred to a general hospital: The workshop participants wanted staff to have a better knowledge of a person, with information being taken in to account in planning for admission and discharge, and in passing information from place to place. The role of relatives and carers, and their knowledge of the person, was also noted.

Unnecessary admissions of people with dementia should be reduced but people with dementia should not be discriminated against if they would benefit from admission: Avoid admissions where possible by anticipation and provision of community support. Where necessary, however, there should be no barrier to admitting people with dementia to receive treatments they require.

In hospital: proactive care planning with and for people with dementia (and their carers) during admission. This may also include people with cognitive impairment who do not have a formal diagnosis of dementia – for example people with delirium: Ensure that the admission process meets the needs of people with dementia, and that appropriate time is taken and relevant information used. The role of families and carers was again stressed, including their role in providing information on people who may have a delirium.

Better assessment, treatment and management in hospital of frail people (often with multiple physical and other problems, who have suspected dementia): Make the best use of an admission, and provide good quality, appropriate care that addresses all relevant problems wherever possible.

Improved knowledge and skills of all staff dealing with people with dementia: Good management while in hospital. This introduced the idea of Dementia Champions in each clinical area.

Reduce the risk of people with dementia experiencing an adverse outcome during admission: This included a focus on delirium, and appropriate use of medication.

Better care for people with dementia should be promoted in general hospitals: Including availability of a mental health liaison service.

Workshop Response

There was general support for the importance of most of the measures. Themes which were mentioned in more than one of the workshops were: early diagnosis; staff training; personalised care; community support; respite care and removing stigma.

People with dementia identified dementia in younger people, young carers and assistive technology as possible issue for greater focus.

Carers identified information availability and carer support as key in four of the five workshops. Listening to carers, work on stigma and awareness, early diagnosis and work with care home staff were also noted to be priorities. Identified gaps included respite care, services in rural areas, dementia in younger people, and post-diagnostic support.

Other Responses

Cameron Stark and Maxine Johnston (of Alzheimer Scotland) reviewed reports from various workshops, consultations and research reports that were available to Alzheimer Scotland. There were clear, repeated themes that reflected the agreement and priorities from the Strategy Workshops.

Prevention

As noted above, the major population risk factors for dementia are known, although the mechanisms by which they increase dementia risk are not well understood. There was general support for incorporating preventative work on dementia in to general lifestyle health improvement work.

Health improvement for people with dementia was also raised, and related to attitudes to people with dementia, discussed further below. If the life of people with dementia is not valued by society, then there is less likelihood of preventative work on other illnesses in people with an existing dementia diagnosis.

Recognition and Early Identification

Comments on this were again partly tied to issues of stigma. Dementia was a ‘dread diagnosis’, which was resisted by many people. There was general support for increasing community awareness of dementia symptoms, and for signposting routes in to care and support. This was linked to a need for explanations of the value of timely diagnosis. If people believed there were no available treatments, and no benefit from timely diagnosis, then this both increased fear and decreased incentives to identification and diagnosis.

Diagnosis

Access to diagnostic services remains an issue. In some cases it takes people a considerable length of time to move through this process, and to receive a diagnosis. In some cases this will relate to clinical presentation, but at other times it seems to be because of system problems in recognition of symptoms, referral or availability of diagnostic services. There was a general expectation that diagnosis should be rapid, wherever that was clinically possible.

Post-diagnostic Support

Being diagnosed with dementia was very distressing, for both the person with dementia and their family. People wanted and expected clear explanations, good information and good support. There was general agreement that the form of the support should be flexible, rather than trying to shoehorn people into a pre-defined support structure, so that people could access group, individual or written information and support as they preferred.

General Health Care and Treatment

Many people with dementia had other health problems. People responding to consultations expected access to the same standard of care, support and treatment for people with dementia as for other people. They also expected care which focussed on the needs of the individual, with services adapting to their needs, to ensure that they could be provided with care.

General hospitals were mentioned in several contexts. Some people reported excellent experiences, but there was also evidence of people who were not treated well during their admission, or whose needs were not recognised and dealt with appropriately. Ensuring good access to general health care from people who understood the needs of people with dementia, both in the community and during any hospital admissions, was seen as very important.

The importance of regular general health, including mental health, reviews were generally favoured.

Therapeutic Interventions to Tackle Symptoms of the Illness

People described limited access to therapeutic interventions, particularly for psychological interventions. In some cases people were not aware they were available, and in others it had proved difficult or impossible to access them. Generally, respondents wanted wide availability of interventions, linked to a pathway from diagnosis.

This included access to support for understanding and managing stress and distress and its possible impact on behaviour. Some respondents felt that skills in services, including hospitals and care homes, were limited, and that staff did not always respond appropriately to behaviours of this type.

Support for Carers

Family carers often took on an enormous workload to support a person with dementia. However, many people with caring responsibilities reported that it was very difficult to obtain support when they needed it, and particularly at times of crisis. Their needs were not considered in some cases, and some people felt they were taken for granted.

Carers had information and educational needs, as well as general support needs, and wanted to be able to access information and support in ways that suited them, when they wanted or needed to do so. Respite arrangements were also raised as an important issue, and this was very consistent across responses.

Supporting the Person

Interactions with, and support from professional carers was very important. Staff described time pressures, without adequate allowance for travel times in some cases, particularly in rural areas. This could result in very little time to spend with people.

People with dementia and their carers described excellent support in some cases, but major problems in others. Continuity of carers and frequent unexplained changes of personnel were a problem. Fitting people in to service processes was a constant annoyance for some, such as helping people to bed at 8pm, rather than at a time that suited them. There were reports of poorly trained staff, with rapid turnover, although others described good care. There was considerable interest in self-directed care in some consultations, and a general expectation that services should be much more tailored to the individual and their needs than was currently believed to be the case.

Housing and the Home Environment

Recognising the housing needs of people with Dementia and their carers should be an important consideration in planning and delivery care. Aids and adaptations could be difficult to access, and sometimes increased time spent in hospital, with consequent increased risk, or resulted in increased risk of falls. Telehealth and telecare were generally well received, and many carers regarded systems such as Health Call as a useful support.

Maintenance of houses was mentioned, with families looking for clear routes of support.

Community Connections

Social interactions were very important. Some families felt isolated and alone. In rural areas in particular, transport could be an enormous problem in accessing support, with long journeys for a short period of time spent at a community centre. Generally, local access was much preferred, and services which allowed people to stay at home as long as reasonably possible.

This also related to work on stigma. Some people felt that they were treated very differently because they had dementia, and there was an expectation that services would work to reduce stigma and to make communities as responsive to the needs of people with dementia.

Summary

There have been numerous surveys and workshops aimed at people with dementia and their carers. The themes in responses appear very consistent. People wanted care that was based around the affected person and their families, which was responsive to their needs and individual requirements, and which respected them as a person. They wanted care that reflected human qualities of caring and concern, and which did not treat them as an inconvenience.

Awareness work and good diagnostic processes are widely supported. Excellent information for carers and people with dementia, including practical information on benefits and fees, need to be available. Access to care is important, and people wanted interventions to be accessible wherever they lived. Respite care was important, and this was a difference from the emphasis of professional reports. Community care of all sorts was mentioned, and timely access to specialist support and also inclusion in the local community wanted.

Carers felt strongly that their views should be considered carefully, and their expertise acknowledged. Care in general hospitals was mentioned repeatedly, as was training and support for staff in care homes.

7 Recommendations

Current predictions suggest a very substantial increase in the number of people with dementia in Scotland. The prevalence in risk factors in future cohorts of older people is likely to have an impact on this. The possible range of increase is important for planning and to allow prioritisation of possible prevention efforts.

The Scottish Public Health Network should consider commissioning work to model the increase in dementia in Scotland under different assumptions, including the potential Scottish impact of different preventative interventions.

The projected increase Scotland's older population and projected increase in the numbers of people living with dementia will have an important impact on health, social care and other public services.

The Scottish Public Health Network should consider including estimates of future service demand into work on the likely number of affected people.

Cognitive impairment is one of the most consistent predictors of the intensity of care needs in older people. The expected increase in the number of people will result in a disproportionate increase in population care requirements.

All Community Planning Groups should incorporate careful consideration of the likely impact of the increase in dementia in to their planning assumptions. This should be informed by direct involvement/representation of people with dementia and carers.

While increasing age is the single most important population level risk factor for dementia prevalence, there is good evidence that other risk factors interact with this. Vascular risk factors seem to be particularly important. There is no current evidence to prove that reductions in vascular risk will inexorably result in decreases in dementia prevalence rates. Given the general benefits of vascular disease risk factor reduction, however, it is sensible to continue to promote work on this area, and to explain the evidence to the Scottish public.

NHS Health Scotland should continue to support work on risk factor reduction, including communicating the available evidence on dementia risk.

Timely diagnosis is an important part of the Scottish Government's strategy on dementia care quality. Engaging General Practitioners in this work remains important. While there is limited current evidence of clinical benefit of early diagnosis, it is important to explain to staff in Primary Care, and particularly to General Practitioners, how timely diagnosis supports Government intentions to provide effective care for people with dementia and their families. The Scottish Dementia Working Group stressed that they receive consistent feedback from people with dementia and carers on the value of early diagnosis**.**

The Scottish Government should maintain clear routes of communication to General Practitioners and other community staff about the benefits for seeking a timely diagnosis.

Psychological therapies for dementia are available in most areas, but are not consistently delivered, publicised and accessed. Given the evidence of benefit, it is important to make services easily available, throughout all stages of the illness, initially linked to post-diagnostic support, but accepting that different patients and families will seek support at different stages of their illness.

The Scottish Government and NHS Scotland should prioritise work to increase the availability of, and ready access to therapeutic interventions.

Anti-psychotic drugs have significant risks to people with dementia. While it sometimes clinically appropriate to prescribe, the Scottish Government and NHS Scotland should continue to make the information on psychotropic prescribing available to prescribers, and to promote other strategies for supporting people with challenging behaviours in both community and care home settings.

The Scottish Government should continue to prioritise work on prescribing psychoactive medication for people with dementia, and to provide good information to prescribers, and to support other intervention strategies where possible.

It is difficult to benchmark service availability in Scotland. There is good work available on mental health service benchmarking, but it can be difficult to compare services because of differences in service definitions and recording.

The Scottish Government should continue to improve benchmarking data, to allow easy comparison between areas. Service planning and commissioning should be informed by a full knowledge and appreciation of existing services, community based assets, and resources in order to maximise these, avoid duplication, utilise skills at local level and optimise partnership working.

Carers often mention the quality of care from general hospital, community and care home staff, and report that, while many staff members are excellent, some appear to have limited knowledge of dementia and dementia care.

The existing Scottish Government focus on staff training is welcome. It should be maintained in the future iterations of the national strategy. Local implementation groups may be useful in co-ordinating training plans across sectors.

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