



Delivering Integrated Dementia Care: The 8 Pillars Model of Community Support

Dementia Practice Coordinator – a named, skilled practitioner who will lead the care, treatment and support for the person, and their carer on an ongoing basis, and their role consists of the pillars, coordinating and ensuring effective support and access to all the pillars, coordinating and ensuring effective support and access to all health and social care interventions of the symptoms of the dementia-specific delay deterioration, maximise coping, maximise independence and improve quality of life.


Mental health care and treatment – access to psychiatric and psychological services to maintain mental health and wellbeing.

Environment – adaptations, aids, design changes and assistive technologies.

Personalised care – flexible and person-centred services that promote independence.

Support for carers – proactive approach to supporting people in the role and maintain the carer's own health and wellbeing.

General health care and treatment – regular and proactive review and management of general well-being and physical health.



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Foreword

In 2010, the Scottish Government launched the first National Dementia Strategy for Scotland. Alzheimer Scotland has been part of a considerable collaborative effort to ensure the success of this Strategy and key to this has been the involvement of people with dementia, their families and carers.



Scotland has made significant progress in the Strategy's priority areas of acute hospital care and post-diagnostic support. We were delighted that the Government adopted our Five Pillar Model of Post-Diagnostic Support. It is our hope that post-diagnostic support based on this model will lead to major improvement in the lives of people who are diagnosed with dementia and their families and friends.

This report builds on this groundbreaking work and offers a clear, strategically connected and fully integrated approach to supporting people with dementia and their families who now require community-based support. As the integration of health and social care moves forward we must embrace the positive opportunity it offers to improve community support arrangements for people with dementia and learn from the good practice examples that already exist in Scotland.

This report sets out the opportunity we have and presents an Eight Pillars model that will enable health care interventions to work hand-in-hand with social care interventions. It shows how dementia is an illness that has many social implications. It demonstrates how these can be tackled most effectively through a model that brings together and coordinates the full range of health and social care interventions required to meet individual needs. It is our considered view that a bio-psychosocial understanding of dementia is the best way to begin to develop such a framework and model for engagement.

We wish to work alongside our partners, the Scottish Government, NHS boards, local authorities and other bodies, to ensure they use the Eight Pillars as a portal to deliver equal access to the best possible treatments and interventions for each person. Together we must continue to build a level of consistent therapeutic, high-quality personalised support services that are aligned and used to best advantage to tackle symptoms of dementia. Only through doing this can we be sure that we are using resources to the best possible effect to enable people to live in their own homes, in their own communities and with their families for as long as they choose.

Anything less than this is not true equality; and nothing less than this satisfies the basic human rights of people with dementia and their families to live well with dementia as equal and valued citizens of Scotland.

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1. Introduction

This report sets out an integrated and comprehensive, evidence-based approach to supporting people with dementia and their carers in the community. Dementia is a complex condition that impacts on the lives of 84,000^a people in Scotland with the illness, and their partners, families and carers. Effectively tackling the symptoms and consequences of dementia requires a coordinated range of health and social care interventions. The 8 Pillars Model of Community Support for Dementia tackles the full range of factors that influence the experience of the illness.

At a time of demographic change and increasing dementia prevalence, it is essential to build the resilience of carers and people with dementia so that they can remain in the community for as long as possible. We must do this in a way that facilitates independence, recognises citizenship and the right to participate fully in society.

Scotland's National Dementia Strategy¹ has been highly effective in improving the support for people with dementia in its key target areas of post-diagnostic support and care in acute hospitals. This report sets out a vision for how the care of people living at home with moderate to severe dementia can be similarly transformed in Scotland.

1.1 Outline of report

Chapter 2: The nature and experience of dementia

Provides an understanding of dementia and identifies the factors that influence the progression of the illness. It demonstrates why neither a medical nor a social model of dementia is adequate; a bio-psychosocial approach is required to understand the subjective experience of the illness and appropriately target interventions.

It also demonstrates why caring for a person with dementia is a unique experience influenced by both objective and subjective factors. The individual circumstances of the carer must be understood in order to provide effective support.

Chapter 3: Where we are now

Looks at where we are now in relation to supporting people with dementia and their carers in the community. It demonstrates why the prevalent construct of care fails to recognise community support as a resource to facilitate resilience and promote independence.

A lack of a joint practice approach, combined with a legacy of people with dementia not being treated as full citizens, has led to a fragmented range of supports that often fail to address the full picture.

The integration of health and social care provides an opportunity for a joint approach to coordinate the interventions required to build the resilience of people with dementia and their carers in the community.

^a Estimated prevalence based on EuroCoDe (Alzheimer Europe (2009) – see references).

Chapter 4: Community support model

Outlines the 8 Pillars Model of Community Support for people with dementia living at home. It follows a bio-psycho-social understanding of dementia by tackling the full range of factors that influence the experience and impact of the illness.

Each factor of the illness influences every other factor, and impacts on the overall health and wellbeing of the person with dementia and the carer. Supporting quality of life and independence and building the resilience of the whole family requires the combination of all eight pillars of community support:

Pillar 1: The Dementia Practice Coordinator

Pillar 2: Therapeutic interventions to tackle the symptoms of the illness

Pillar 3: General health care and treatment

Pillar 4: Mental health care and treatment

Pillar 5: Personalised support

Pillar 6: Support for carers

Pillar 7: Environment

Pillar 8: Community connections

Chapter 5: Conclusion and recommendations

Provides recommendations on the way forward and implementation of the 8 Pillars Model of Community Support. The Scottish Government should adopt the 8 Pillars Model and ensure its implementation by making it a key target and outcome for the integration of health and social care. The 8 Pillars Model should form a key priority for the next National Dementia Strategy to be published in 2013.

Local authorities and NHS Boards should realign their joint resources using the 8 Pillars Model to deliver effective dementia care as part of the integration agenda. They should embed the Dementia Practice Coordinator role as a key component to ensure every pillar of care and treatment is offered to each individual in a coordinated way.

2: The nature and experience of dementia

Summary

- Dementia is the interrelationship of neurological damage and psychosocial factors; the experience of dementia is subjective and unique to each individual.
- Whilst mood and behaviour may be profoundly affected, personhood is not; the individual remains the same equally valuable person throughout the course of the illness.
- The negative impact of failing to recognise personhood can be seen in “malignant social psychology”² and a culture of support which fails to see people with dementia as having the same rights as every other citizen.
- A bio-psychosocial representation of dementia provides an appropriate model to capture the factors that determine the nature of dementia, progression of the illness and the appropriate interventions.
- Caring for a person with dementia is also a subjective experience; it is influenced by many factors, including the symptoms of the illness and individual circumstances. Interventions to support the carer must meet their specific needs and circumstances in order to be effective.

2.1 What is dementia

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 Organization³

Dementia includes a range of brain diseases that are typically of a chronic and progressive nature. The term dementia is also used to describe a range of disease symptoms relating to deterioration in cognitive function, behavioural changes and functional limitations. It is caused by diseases and injuries that primarily or secondarily affect the brain.

Although dementia predominantly affects people in older age, it is an abnormal condition and not a natural part of ageing^b. The experience of dementia is subjective and unique to each individual; it is determined by a number of factors including neurological damage and the thoughts, feelings and behaviour of the individual, within their social context.

^b Age is the greatest risk factor for dementia; however, there are an estimated 3,000 people with dementia in Scotland aged under 65.

2.1.1 Diseases

The two most common forms of dementia are considered to be Alzheimer's disease and vascular dementia. There are also a number of rarer^c forms of dementia⁴; fronto-temporal degeneration and Lewy body disease being the most common⁵. Alzheimer's disease is most common across all age groups; fronto-temporal and Lewy body dementia occurs more commonly in younger people^d.

Despite the development of more sophisticated means of medical assessment, dementia often defies distinction between the different illnesses.

Vascular dementia has traditionally been separated from Alzheimer's disease and thought of as being secondary to stroke and vascular disease. In recent years, evidence has suggested that vascular risk factors contribute to Alzheimer's disease⁶. It is also considered likely that pure Alzheimer's disease and pure vascular dementia are relatively rare.

The majority of people are likely to have mixed dementia characterised by "multiple cerebral pathologies with prominent vascular involvement"⁷.

2.1.2 What happens in dementia

The fundamental causes of dementia are not yet known. In Alzheimer's disease, the chemistry and structure of the brain change; protein plaques and tangles develop and form clumps, leading to death of brain cells. In vascular dementia, there are problems with the blood supply which destroys small areas of brain cells; this can occur over time or suddenly, following a stroke.

With Lewy body dementia, tiny abnormal structures develop inside nerve cells, which result in degeneration of the brain tissue. In fronto-temporal dementia, damage is focused on the front part of the brain, the areas responsible for control of behaviour and language.

^c Rare disease are those presenting a prevalence of less than 5 per 10,000 population (European Commission (2008) – see references).

^d Those aged under 65 years.

2.1.3 Disease manifestations and symptoms

Dementia is the interrelationship of neurological damage and psychosocial factors. Each person with dementia is unique and will be affected in their own way; the progression of the illness will vary between people and the different diseases. Dementia generally develops slowly and is not always obvious in the early stages.

The range of disease symptoms are set out below. People with dementia will not experience all these symptoms; the degree to which they are experienced will also differ between individuals.

Cognitive Impairment	Behavioural Manifestation	Functional Limitations
Memory	Personality, behavioural and mood changes	Self-care
Confusion	Apathy	Activities of daily living
Concentration	Anger	Balance and gait
Disorientation	Anxiety	Motor skills
Language	Sleep disturbance	Visuo-spatial difficulties
Learning capacity	Delusions	
Judgement	Hallucinations	
Thinking	Physical aggression	
Comprehension	Depression	
Calculation	Disinhibited social behaviour	
Time perception		

Progression of the illness is often separated into early stage (mild), mid-stage (moderate) and late stage (severe). This can be useful to provide an outline of typical symptoms and degree of difficulties associated with disease progression; it can “provide structure in peoples understanding of what is happening”⁸. However, these divisions will not always relate to the degree of disability encountered at each stage; this will depend on each individual and their unique set of circumstances.

In addition, some forms of dementia cannot be characterised by such distinct stages. Vascular dementia can be associated with gradual decline in functioning or sudden decline following a further stroke. Those with early stage Lewy body dementia may experience visual hallucinations and have difficulty with balance and judging distance; this disease can progress more rapidly. In the early stages, people with fronto-temporal dementia generally experience behavioural changes associated with damage to the front of the brain; later in the disease, symptoms will usually appear to be similar to those of Alzheimer’s disease.

2.1.4 Treatments

There are a small number of drug treatments^e available to treat some types of dementia; these treatments do not modify the disease progression and will not be effective for or tolerated by everyone. However, they can have beneficial effects in treating the symptoms. For some individuals they may delay or slow symptoms for six months to a year; others will see benefits for much longer. For people with vascular dementia, medication to treat the primary condition such as stroke or high blood pressure may slow the progression of the dementia.

However, in contrast to other diseases, the main therapeutic intervention for dementia is human care and treatment. This encompasses a range of therapeutic, psychosocial and psychological treatments. The purpose of these interventions is to tackle the symptoms of the illness, delay deterioration and enhance coping.

2.1.5 Prevalence of dementia

Whilst there are approximately 40,000^g currently identified cases of dementia, based on best available evidence, there are estimated to be 84,000¹⁰ people with dementia in Scotland with an incidence of around 8,400 in 2012^f. A UK based study reporting the prevalence of dementia and severe cognitive impairment in the year before death in a large population sample aged 65 years and over, found an overall prevalence of dementia at death of 30%, with a strong increasing trend towards the oldest population¹¹.

The prevalence of dementia will increase as a result of demographic changes; based on current estimates the number of people with dementia will double within the next 25 years. These projections are based on previously observed prevalence within populations and do not take potential changes in prevention into account.

“Compression of morbidity”¹² suggests increased average life span may delay chronic illness to nearer the end of life. The evidence required to support solid conclusions about the expansion or contraction of illness in later life does not presently exist¹³. Findings of a recently published study suggested dementia prevalence had decreased slightly^g between 1990 and 2005¹⁴. This study suggests it cannot be assumed the increase will be wholly proportionate to demographic changes.

Given this complexity, it is most appropriate to consider the increasing dementia prevalence within the context of the short to medium-term. The number of people with dementia in Scotland is projected to increase to 94,000 by 2017 and 108,000 by 2022; with incidence of 9,400 and 10,800 respectively. This represents a 12% increase by 2017 and a 29% increase by 2022^h.

^c Donepezil, Rivastigmine, Galantamine and Memantine.

^f Prevalence is an epidemiological measure of how frequently an illness occurs in a population at the point of measurement; it is calculated by dividing the number of persons with the disease or condition by the number of individuals examined. Incidence represents the rate of occurrence of new cases; dementia incidence has been calculated by assuming a disease trajectory of 10 years.

^g Statistically significant differences were not found between the two decades. However, age-adjusted dementia prevalence rates were consistently lower in latter sub-cohort.

^h Based on 2012 prevalence.

2.1.6 Recognising personhood

Philosophical debates on dementia have largely focused around the fundamental nature of beingⁱ and what constitutes personhood. One body of opinion originated from the view that in order to identify oneself as the same person over time requires memory¹⁵; a person with advanced dementia could therefore be considered to be a different person. A more holistic view of personhood includes other factors such as bodily identity¹⁶ and interpersonal identity through established relationships¹⁷.

These social connections and the “embodiment”¹⁸ within a physical presence provide a strong foundation for viewing an individual as the same person throughout the course of the illness.

The failure to recognise personhood and the negative impact of inappropriate care-giving results in “malignant social psychology”^j; this includes labelling, disempowerment, infantilisation, invalidation and objectification¹⁹. One of the reasons behind this malignance is failing to see a person and not showing the respect that properly accords a person²⁰.

Even when a person seems to have lost a significant part of what made them a unique individual, core elements of their identity will remain. These “characteristic gestures and ways of doing things are what keep alive the sense of the individual they once were, even if the more sophisticated levels of that individual have been removed”²¹.

This has important implications for the approach to providing support and what people require in addition to the basics of daily living. A person’s sense of self and self-respect can be fostered through “reinforcing any remaining elements of conscious self-identity”; less conscious elements in a person’s identity can be preserved through physical surroundings to retain “physical links with their past, which help to support a sense of personhood”²².

Whilst mood and behaviour may be profoundly affected, personhood is not; the individual remains the same equally valuable person throughout the course of the illness. Interventions to support the person with dementia should honour their personhood and right to be treated as a unique individual.

ⁱ Metaphysics.

^j Social psychology is malignant because of its effects upon the person.

2.1.7 Experience of the illness: towards a model of dementia

A relevant model of dementia is essential to capture all the factors that may influence the experience and progression of the illness. This can enable appropriate planning to ensure interventions to meet individual needs.

Dementia is amongst other things a potential disability²³. A medical model of disability locates the “problem” with the individual. The medical model of dementia assumes dementia is a disease caused by organic problems that should be treated and managed according to medical authority. However, the symptoms of dementia cannot be solely explained in relation to neuropathology; psychosocial factors must also be taken into account²⁴.

A social model of disability places responsibility on society for failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account²⁵. However, whilst the organisation of society and the way people with dementia are treated can create “excess disability”²⁶, neurological factors must be contained within any fitting model of dementia.

The World Health Organization’s classification of functioning, disability and health recognises the need for a bio-psychosocial model to “synthesize what is true in the medical and social models, without making the mistake each makes in reducing the whole, complex notion of disability to one of its aspects”²⁷.

Kitwood²⁸ provided a dialectical model of dementia to highlight the inter-relationship between neurological and social-psychological factors. He proposed a complex interaction between five factors^k that will be unique to each individual. Bender and Cheston²⁹ provide a three stage model to describe the subjective world of a person with dementia: (1) the feelings engendered by dementia^l, (2) behaviour provoked in response to the process of decline, and (3) the person’s emotional reaction, which is dependent on the extent of their cognitive impairment and their social context.

A “self-regulation model of adjustment to illness” suggests that individual differences in coping and responses are dependent on the views the person holds in relation to the illness³⁰. Testing of this concept with people in the early stages of dementia supports the relevance of psychological and social factors in the daily lived experience of the illness^{31 32 33}.

Spector and Orrell develop the bio-psychosocial approach to provide a model for identifying factors that may lead to improvement or deterioration in the person³⁴. They provide a pragmatic tool to identify the fixed factors (not amenable to change) and tractable factors (may be amenable to change). This presents dementia as “malleable” with “change, adaptation and improvement” possible³⁵. Both the fixed and the tractable factors will “influence the point at which the symptoms of dementia begin, the speed and nature of the deterioration and the appropriateness and effectiveness of interventions”³⁶.

^k Clinical manifestation of dementia = Personality (resources for action) + Biography + Health + Neurological Impairment + Social Psychology.

^l Includes at least four discrete stages: anxiety, depression, grief and despair/terror.

2.2 Carers of people with dementia

Caregiver burden is a multidimensional response to physical, psychological, emotional, social and financial stressors associated with the care-giving experience. The caregiver's perception of the burden, rather than the perception of other family members or healthcare providers, determines the impact on his or her life³⁷.

Most care for people with dementia is provided by informal carers, typically a family member. The responsibility for caring is often accepted for emotional reasons, not because the carer feels expert or comfortable with the type of care required.

The main carer may be the spouse or partner of the person with dementia; carers are also often the son or daughter. These two sets of circumstances are likely to present different types of issues. A partner may have their own health problems to contend with. Adult children are likely to be economically active and possibly not living with the person with dementia. The families of younger people with dementia are likely to have additional sets of issues; they may have dependent children and financial commitments associated with younger age, such as a mortgage.

The carer's life often becomes restricted and determined by the act of caring; they may reduce or give up employment, restrict time with friends and family and sacrifice their own pursuits and hobbies. Caring for a person with dementia is complex and demanding; whilst carers generally report a greater number of physical health problems and worse overall health^m, carers of people with dementia are also at increased risk of psychological ill health³⁸.

Factors associated with increased carer burden are objective (relating to the tasks or activities of caring) and subjective (representing how the carer feels about their role)³⁹. Increased risk of institutionalisation of the cared for person is also associated with a wide range of demographic factors, such as the relationship to the cared for person, and psychosocial factors such as problem behaviours in the person with dementia⁴⁰.

Living with a carer has been shown to have a protective effect in delaying the person with dementia entering institutional care⁴¹. Carers adopting a problem-focused approach to responding to difficulties associated with caring, as opposed to an emotional-focusedⁿ approach, were more confident about their effectiveness⁴². Carers who are more satisfied with their social interactions report fewer negative psychological symptoms⁴³. These factors demonstrate the importance of providing interventions to support the carer; they can have beneficial effects for the person with dementia, the carer and for public resources.

^m Compared to non-caregiver controls.

ⁿ Problem-focused coping strategies aim to confront the reality of the major strain. Emotional-focused coping strategies deal with the feelings associated with the major strain.

2.3 Conclusion

A bio-psychosocial approach to understanding the experience of dementia provides an appropriate model to identify the factors that determine the nature of dementia, progression of the illness and appropriate interventions.

The symptoms of dementia require a full range of health and social care interventions to delay deterioration, maintain health and wellbeing and enhance coping. This leads on to consideration of current approaches to supporting people with dementia and carers in the community, which are discussed in the following chapter.

3: Where we are now

Summary:

- People with dementia and their carers do not always receive the health and social care interventions required to support them to live in the community.
- The prevalent construct of care provided fails to recognise community support as a resource to facilitate resilience and promote independence. Poor quality community services can increase the challenges of living with dementia.
- The integration of health and social care provides an opportunity to create a structured, coordinated and strategic approach to community support for people with dementia and their carers. This will help enable the person with dementia to remain in the community for as long as possible.

3.1 Introduction

The previous chapter showed that the interventions required to support people with dementia in the community cover a range of health and social care needs. However, there is currently no coordinated approach to bringing the strengths of health and social care together to treat the symptoms of the illness. Crucially, there is no integrated practice direction when people start to decline.

This lack of a joint practice approach, combined with a legacy of people with dementia not being treated as full citizens, has led to care often failing to support people in the most effective ways, and as a result, failing to use scarce resources efficiently.

The integration of health and social care presents an opportunity to provide a coordinated approach to enhancing the coping and resilience of people with dementia and their carers living in the community, in a manner that promotes their human rights.

3.2 Current community support

Local authorities are the commissioning body for most of the support services provided for people with dementia living in the community. However, this is only part of the full range of interventions required to support people to live well.

In some areas, support is provided through generic care services. These are based on economies of scale, with high volume contracts and generic quality indicators. In these circumstances, we fail to recognise community support as a potential resource to facilitate resilience and promote independence; inappropriate services can exacerbate the challenges of living with dementia.

When provided in this way, short time periods are given to care workers to carry out tasks, with the majority of home care being task orientated⁴⁴. Carrying out tasks for the person creates dependency; the opportunity to maintain function in activities of daily living is then lost and people become de-skilled – thus exacerbating the symptoms of the illness.

There can be frequent changes^o in care workers coming into the home, which is highly inappropriate for a person with dementia⁴⁵. In addition to creating confusion, lack of consistency in care workers denies the opportunity to create supportive relationships with the person and their partner, family and carer.

This task-based approach to supporting people with dementia has missed the opportunity to shape paid-for support in a way which works with and enhances the natural supports in people's lives.

The vast majority of support for people with dementia is provided informally, typically by family members. National statistics⁴⁶ show that only a small proportion of people with dementia receive formal community support^p. Eligibility thresholds can result in people with dementia failing to qualify for support until their condition has deteriorated⁴⁷. Public resources are generally aimed at those with the highest level of need, but even amongst this group, services are only being used by a relatively small proportion of people with apparently similar levels of need⁴⁸.

Audit Scotland's recent report on the commissioning of social care⁴⁹ found an absence of strategic commissioning based on analysis of local needs and a lack of joint approaches with NHS boards. Local authorities did not fully analyse the costs, capacity, accessibility, quality and impact of in-house, voluntary and private sector provision. There was also considered to be a danger of focusing on reducing costs and short term decisions, to the detriment of giving sufficient regard to the range and quality of services, assessing the impact of services on individuals and preventative services.

Demographic changes and financial challenges mean that current models of care are not sustainable in the longer term⁵⁰. A lack of effective support in the community can result in early admission to a care home. An estimated 40% of people with dementia live in some form of institutional care; people with dementia are also thought to account for 70% to 90% of the care home population⁵¹. There is an unarguable ethical argument for supporting people with dementia in the community, but there is also a strong financial case: an increasing care home population has significant financial implications for public resources.

3.3 Integration of health and social care

The integration of adult health and social care⁵² provides an opportunity to coordinate the interventions required to support people with dementia and their carers in the community. Now is the time to ensure the proposed integrated health and social care partnership budgets can facilitate seamless support to ensure the range of support needs of people with dementia and their carers are not overlooked.

The move towards community capacity building and proportionately fewer resources for institutional care requires a coordinated approach to support people with dementia in the community. It will be essential that a dementia strategy is set at the partnership level as part of the national agreed outcomes in order to avoid local divergence in the scale and quality of dementia support.

^o A recent case of 106 different care workers providing home to care for a man with dementia over the period of one year.
^p 3,358 people with dementia received home care in 2011 according to Scottish Government national statistics (Scottish Government (2011a) – see references). This represents a 9% decrease from 2006 (Alzheimer Scotland (2008) – see references).

3.4 Conclusion

People with dementia and their carers do not always receive the range of health and social care interventions required to build their resilience and support them to live in the community. Crucially, the symptoms of the illness are not being treated and carers are not receiving essential support that could enhance their resilience.

It would be difficult to contemplate a hospital ward where doctors did not communicate treatment requirements to nursing staff. However, this is what currently happens with health and social care for people with dementia – there is no structure for managing and coordinating the required health and social care interventions. This results in a fragmented range of supports that often fail to address the full picture, and consequently are less effective both in human and financial terms.

The integration of health and social care provides an opportunity to create a structured, coordinated and strategic approach to community support for people with dementia and their carers to ensure they can remain in the community for as long as possible. The following chapter of the report introduces a clear model for how this can be achieved.

4: The 8 pillars model of community support for people with dementia

4.1 Introduction

The 8 Pillars Model of Community Support for people with dementia living at home follows a bio-psychosocial understanding of dementia by tackling the full range of factors that influence the progression of the illness. It acknowledges the subjective experience for both the person and the carer. It also honours their right to personhood, full citizenship and optimum participation in society.

“Excess disability”⁵³ is created when people with dementia do not receive appropriate care and treatment for the symptoms of the illness. Without the right support, there is a gap between how people actually function and how they could potentially function⁵⁴. It is important to see the potential to improve the lives of people with moderate to severe dementia living at home.

Each factor of the illness influences every other factor, and impacts on the overall health and wellbeing of the person and his or her carer. Supporting quality of life and independence and building resilience for the whole family requires the combination of all eight pillars of community support.

4.2 Who will require this approach?

The one year post-diagnostic guarantee^q will provide those newly diagnosed with early stage dementia with support in adjusting and managing the likely impact of the illness, both emotionally and practically. It will put people in the best possible position to manage their symptoms and the practicalities of their lives for a period of time, with access to low-level forms of support and signposting, until their condition progresses to a point where they begin to need services.

This 8 Pillars Model of Community Support will then provide a coordinated approach to supporting people to remain at home for as long as possible.

There will be a proportion of those newly diagnosed who will require the community support model either immediately after diagnosis or in place of post-diagnostic support, as some people are diagnosed at a later stage, or progress more rapidly in their dementia.

Based on current estimated prevalence and patterns of care^r, around 25,000^s people with dementia would theoretically require the community support model in 2012. However, current levels of diagnosis mean there is unlikely to be this number of identified cases within the community at this time.

^q The Scottish Government has provided a guarantee that people receiving a diagnosis of dementia would be offered one year of post-diagnostic support based on a 5 Pillars Model established by Alzheimer Scotland, from 2013 onwards.

^r An estimated 40% of people with dementia will be in some form of institutional care.

^s 84,000 minus the proportion estimated to be living in care homes (33,600) and those at the early stage of the illness not yet requiring support to live in the community (last 3 years incidence of dementia).

The current number of people with dementia receiving social care support is a good starting point for estimating those requiring the 8 Pillars Model. There will also be additional people with dementia who are known to community health services^t who are ready for this approach.

The number of people diagnosed with dementia will continue to increase. The structured approach to post-diagnostic support, the planning of future care needs and the impact of the 8 Pillars Model will increase the proportion of people being supported in the community. There will be an increase in both the proportion^u and the number^v of people with dementia remaining at home.

Local authorities and NHS boards should plan for a steady increase in the number receiving this coordinated approach to living at home for as long as possible throughout the journey of the illness.

4.3 The 8 pillars model of community support for dementia



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^t Those who are not receiving social care services.

^u Proportionately more people will remain in the community and postpone or avoid entry to institutional care.

^v The number of people will also be greater as result of increased prevalence.

4.3.1 Pillar 1: The Dementia Practice Coordinator

Description

The Dementia Practice Coordinator forms the first pillar of community support. This is a named, skilled, practitioner operating at the Enhanced Level of the Promoting Excellence Framework⁵⁵. They will ensure access to all pillars of support on an ongoing basis as appropriate to each individual, and will coordinate between all the practitioners delivering care, treatment and support.

Each person with dementia will be accompanied throughout their journey by a Dementia Practice Coordinator who will provide an individualised approach to lead the care, treatment and support of the person and their carer. They will be an appropriately skilled worker with the ability to provide, commission and control interventions.

Why

There is currently no coordinated approach to providing support and no joint practice intervention when people start to decline.

People with dementia and their carers do not receive the range of interventions required to support them in the community.

What it will deliver

Building the ability of people with dementia to live well with increasing help and support in the community, and eventually through the end of life and dying well with dementia, requires a range of interventions. The symptoms of the illness mean the care, support and treatment needed spans health and social care. It requires a single practitioner to hold responsibility for ensuring all needs are met and that those working with the person do so in a coordinated way.

The Dementia Practice Coordinator will provide a structured approach to integrate specific supports that will tackle the symptoms of the illness, delay deterioration, enhance coping and prevent crisis. They will identify the critical points when the person and their carer require alternative or additional interventions and harness the contribution of a wide range of practitioners. Linking support together, they will have an overview of each individual's care and treatment.

Who and how

Dementia Practice Coordinators will come from among existing practitioners working within dementia care: community psychiatric nurses, social workers and allied health professionals each have a strong relevant skill set in their own right. These can be built on to ensure a full understanding of all approaches required to tackle the full range of symptoms.

They will benefit from the knowledge and expertise of a range of practitioners. Crucially, the role will involve effective communication with the GP, psychiatry and the wider community mental health team. The Dementia Practice Coordinator will facilitate the transfer of this knowledge and expertise into the design of effective social care interventions.

4.3.2 Pillar 2: Therapeutic interventions to tackle symptoms of the illness

Description

Therapeutic approaches to tackling the symptoms of the illness are essential in order to address cognitive impairments, functional limitations and behavioural problems.

These dementia-specific therapies will aim to delay deterioration, enhance coping, maximise independence and improve quality of life. Therapies include reality orientation, reminiscence therapy, cognitive rehabilitation, validation therapy and cognitive stimulation therapy.

The therapeutic approach also includes access to dementia drug treatments^w to treat the symptoms of the illness, where appropriate and tolerated by the individual.

Why

At present, people with dementia do not typically receive these interventions as part of a therapeutic approach designed to tackle their symptoms. As a result, the evidence base is limited. There is some basis of evidence to support their use, which will develop further as the availability of these treatments is expanded and practice evolves^x.

What it will deliver

Cognitive rehabilitation assists the person to achieve personal goals in relation to making the most of remaining memory and developing compensatory strategies. Clinical efficacy has been demonstrated in the use of goal-orientated cognitive rehabilitation^y 56. Cognitive stimulation therapy can provide mental stimulation in order to improve functioning; there is consistent evidence of benefit to cognitive function^z and some evidence on improvement in quality of life⁵⁷. It has demonstrated an effect on promoting language; improving conversation and communication, which is considered to have generalised benefits⁵⁸.

Physical exercise is important to the general health of people with dementia⁵⁹. Exercise and mobility promotion interventions aim to slow the loss of mobility and strength, prevent falls and improve balance and endurance levels. There is evidence to support physical training improving muscle strength and physical functioning⁶⁰. There is also evidence to support motor stimulation practice postponing decline in the ability to carry out activities of daily living^{aa 61}.

A preventative approach should be adopted to reduce the occurrence of behavioural problems; Kitwood's work on malignant social psychology⁶² identifies approaches that are likely to have a detrimental impact on how the person feels and behaves. Interventions can review the appropriateness of the way others respond to the person or consider environmental changes that may make the person more comfortable. A tailored activity programme⁶³ provides a home-based intervention to reduce behavioural symptoms^{bb}; it has demonstrated good outcomes when combined with carer coping strategy-based support⁶⁴.

^w Donepezil, Rivastigmine, Galantamine and Memantine.

^x Lack of "evidence of efficacy is not evidence of lack of efficacy" (Cooper C, Mukadam N et al (2012) – see references).

^y Intervention group early stage dementia.

^z In mild to moderate dementia.

^{aa} Conducted in a nursing home setting.

^{bb} Activities are based on the person with dementia's biography and capabilities; an occupational therapist trains and supports the caregiver in delivering the intervention.

Where it has not been possible to prevent the behavioural issue, a therapeutic approach should be taken ahead of consideration of drug treatments^{cc 65}. The Newcastle Model provides an individual framework for understanding the cause of the person's behaviours and a process for delivering interventions⁶⁶.

Who and how

The appropriate interventions will be determined by individual circumstances, as assessed by the Dementia Practice Coordinator in conjunction with specialist colleagues. They can be delivered in a group setting or individually, depending on what is appropriate for the particular person and each intervention.

Psychologists can assess and advise the Dementia Practice Coordinator on the type of intervention required. They can also undertake therapies, in both individual and group settings.

Community psychiatric nurses have an important role in providing therapeutic interventions and approaches in assessing and advising on ways of coping with the symptoms of the illness. Occupational therapists are well placed to deliver cognitive stimulation therapy and the approach is in keeping with their professional values⁶⁷.

These practitioners each have an important role in advising the Dementia Practice Coordinator on therapeutic approaches to social care interventions.

^{cc} Antipsychotic drug treatments have been shown to have major negative impact over short-term use (6-12 weeks), including functional restrictions, accelerated cognitive decline and increased mortality (Ballard C, Corbett et al (2009) – see references).

4.3.3 Pillar 3: General health care and treatment

Description

Regular and thorough medical review is essential to maintain general wellbeing and physical health; it will ensure any health problems or illnesses are detected and appropriate treatment provided.

The GP has the key role in early identification of problems; often the first point of contact, they have an essential role in both treatment and referral, where appropriate.

Why and what it will deliver

Undetected illness, pain or discomfort can exacerbate the symptoms of dementia and make life more difficult than it needs to be, both for the person and their carer. Infections can increase someone's level of confusion.

Pain, which someone may not be able to communicate verbally, can cause them to seem agitated, restless or irritable. Agitation can be one of the most distressing neuropsychiatric symptoms for the person and their carer. Effective pain detection and management can play an important role in significantly reducing agitation and the inappropriate use of antipsychotic drug treatments⁶⁸.

Sensory deficits are common in older age; in people with dementia, their impact can be exacerbated by the illness as a result of being unable to interpret the sensory difficulty. Sensory deficits can impact on the level of cognitive functioning and contribute to confusion and delirium. The level of sensory impairment experienced can be reduced by the use of appropriate aids, such as spectacles or hearing devices.

There are particular physical health problems associated with some types of dementia. In vascular dementia, it is important the pre-existing vascular condition is managed effectively in order to maintain health and reduce the risk of sudden decline. Diabetes is a risk factor for dementia; where this is a pre-existing condition, it is essential that diabetes is controlled effectively.

Dementia has not been widely recognised as a terminal illness and the need for palliative care can be overlooked^{dd}. People with dementia require access to good quality palliative care and end of life care to remain at home. The carer also requires specialist intervention to support them to provide appropriate care. Coordinated by the Dementia Practice Coordinator, it requires a multi-disciplinary approach, including specialist nursing, GP and psychiatric services.

^{dd} Palliative care and end of life care are closely related. Palliative care is the period from diagnosis to death; for people with dementia this continues throughout the illness and is more evident in some stages of the illness than others. End of life care is provided in the period shortly before death and should be the continuation of good care provided over the long trajectory of the illness. The trajectory towards death can be protracted in dementia; diagnosis of dying is difficult, the person may have several near death experiences over a period of weeks or months.

Who and how

The mandatory 15 month GP check-up⁶⁹ for people with dementia provides an important opportunity for review.

An on-going proactive approach is also required to manage the health and wellbeing of the person.

The GP will provide a key component in enabling the Dementia Practice Coordinator to effectively coordinate appropriate interventions for the person and their carer.

4.3.4 Pillar 4: Mental health care and treatment

Description

People with dementia require regular review of their mental health in order to detect any problems, promote their mental wellbeing, and treat illness.

Psychiatry has an essential role in assessing, diagnosing and providing appropriate treatment; it also has a crucial role in assisting the carer to cope with change and respond to problem behaviours.

Delivery of this relies on the contribution of the whole mental health team including psychologists, community psychiatric nurses and allied health professionals.

Why and what it will deliver

There is high co-morbidity of dementia and neuropsychiatric symptoms^{ee 70 71}; these conditions can have a detrimental impact on both the person and the carer and are often very distressing.

Mood disorders can appear to intensify the symptoms of dementia. They can act to make the person's memory appear affected, when they may in fact be inattentive to their surroundings as a result of low mood. It is essential these types of symptoms are addressed. Left untreated, low mood can lead to the person withdrawing even further, thus exacerbating the symptoms of dementia in a vicious circle.

Psychiatrists have a key role in assessment, treatment and providing guidance on appropriate interventions to respond to these conditions and behaviours. Delivery relies upon the wider community mental health team.

Psychiatrists and the community mental health team will provide an essential source of knowledge and expertise for the Dementia Practice Coordinator. This skill base will have a significant impact on shaping effective social care interventions to ensure better outcomes for the person and their carer. The Dementia Practice Coordinator will facilitate this transfer of knowledge, so that health and social care operate as one team in tackling the symptoms of the illness.

Who and how

The person may be under the care of a psychiatrist, who will monitor their general mental health, as well as their dementia.

Where the person does not see a psychiatrist regularly, the GP should assess the person's mental health as part of a regular and thorough medical review and should refer as appropriate to the community mental health team.

^{ee} Agitation, anxiety, delusions, depression and hallucinations.

4.3.5 Pillar 5: Personalised support

Description

People with dementia and their carers require personalised and flexible support that facilitates their independence, citizenship and right to participate in society. Support should be delivered proactively and sensitively by skilled workers trained to a minimum of the Skilled Level of the Promoting Excellence Framework⁷².

Why

The vast majority of care and support for people with dementia is provided by informal carers, typically family members. The opportunity to create best value through combining public resources with the natural supports in people's lives is currently not being achieved for the majority.

The prevalent construct of care fails to recognise community support as a resource to facilitate resilience and promote independence. Community support services can be inflexible and inappropriate, creating dependency rather than promoting independence.

What it will deliver

A small level of consistent and high quality dementia-specialist support can complement the natural supports in people's lives. Support should utilise person-centred planning processes and be outcomes-focused to enable people to live well with dementia and ensure their families enjoy as good and inclusive a life as possible.

Provision of services should not be expressed in hours of care; instead, support should be designed in line with the range of approaches to self-directed support set out in the Social Care (Self-directed Support) (Scotland) Bill⁷³. Whether people wish to directly commission their own support or not, the support they are offered must allow flexibility to provide what is truly meaningful for each individual's life.

For some people, support will involve personal care and dementia-specialist day care. There may also be a need for basic home care. Personalised support goes further to enable the person and their carer to have maximum quality of life. It reinforces the right to active participation and citizenship. It provides what is meaningful and relevant for each individual in order to maintain the fabric of their life for as long as possible.

Giving additional time to a person with dementia saves time in the long run; supporting a person to do things for themselves, rather than carrying out the task for them, maintains function and skills in activities of daily living.

This approach to support continues to empower the person with dementia and their family to remain in control throughout the duration of the illness – thus helping to avoid crises and assisting in delaying the need for admission to institutional care.

Who and how

The evolution towards self-directed support will assist people to make best use of combining public resources and natural supports. However, personalised support can be delivered now within the existing system by a range of public, private and voluntary sector organisations – provided there is good assessment and outcomes-focused support planning.

The Dementia Practice Coordinator will assess the person's requirements and ensure support delivers their key outcomes.

Where support is self-funded, the Dementia Practice Coordinator will continue to have a role to assist the person and their carer to design services which support the maintenance of their quality of life.

4.3.6 Pillar 6: Support for carers

Description

The carers of people with dementia require a range of interventions to support them in their care-giving role; this includes education, skills training, coping strategies and peer support.

Carers also require their own health and wellbeing to be considered independently of the person they care for, including their general and mental health, need for respite and right to their own social connections.

Why

The experience of caring is subjective and unique to each carer and person with dementia they care for^{74 75}.

The support needs of the carer will depend on a number of factors, including personal circumstances and relationship to the cared for person^{ff}.

What it will deliver

Carers require increasing support to accept and adapt to the changes to the person with dementia and the impact of this on their lives. Such support requires a coordinated approach to facilitate coping and resilience. Carers may require a wide range of interventions, including counselling, to come to terms with the changed relationship with the person they care for, and information and support around decision making. They may also require more practical training, such as how to move the person whilst protecting their own physical health.

There is both an ethical rationale and a public interest in providing proactive support to carers.

Carers require training in interventions that are effective for people with dementia⁷⁶. Interventions that combine different elements of support, are individually tailored and require the active participation of the carer have been shown to have the greatest benefits^{77 78 79}.

Carers require regular review of their physical, emotional and mental health. In addition to poorer general health, carers of people with dementia are at increased risk of psychological illness⁸⁰. Neurological disturbances and behavioural problems in the person with dementia are particularly associated with increased strain on carers⁸¹.

Carers often lose social contact and can experience feelings of social isolation. Carers who are more satisfied with their social interactions show fewer negative psychological symptoms⁸².

^{ff} The main carer may be the spouse or partner of the person with dementia; carers are also often the son or daughter. These two sets of circumstances are likely to present different types of issues. The families of younger people with dementia are likely to have additional sets of issues.

A tailored activity programme⁹⁹ has been shown to reduce time spent on the activities of caring ⁸³.

Support such as respite to enable the carer to maintain their own social networks, opportunities for peer support and assistance to maintain community connections are vital.

Who and how

Interventions for carers will be delivered across health and social care disciplines. The Dementia Practice Coordinator will identify the individual needs of the carer and link with the appropriate practitioner or service.

⁹⁹ Activities are based on the person with dementia's biography and capabilities; an occupational therapist trains and supports the caregiver in delivering the intervention.

4.3.7 Pillar 7: Environment

Description

Consideration of housing^{hh} issues is an essential component in supporting the person to remain living in the community. It is crucial this is connected with health and social care needs; a proactive and preventative approach must be taken to implementing changes and adaptations to the home.

Adaptations, aids, design changes and assistive technology can help to maintain the independence of the person and assist the carer. They can address some of the challenges caused by the symptoms of the illness, as well as co-existing conditions.

Why and what it will deliver

There are many areas where environmental adaptations or assistive technology may help, provided they are carefully tailored to individual circumstances.

Changes to the home can help the person cope better with the symptoms of the illness and maintain their independence for longer. They can also assist the carer to support the person. Access to appropriate adaptations, aids or assistive technology can help people to remain in their own familiar surroundings for as long as possible.

People with dementia can have difficulty moving around the home as a result of physical, perceptual or cognitive symptoms of the illness. Design changes, often at low cost, can provide preventative measures to reduce the likelihood of accidents and make the home easier for the person with dementia to negotiate.

Assistive technology within and outwith the home can enable people to perform tasks they may otherwise be unable to do. It can also monitor changing needs and provide alerts and information to allow informed response to risks. There are many potential positive outcomes of the use of assistive technology, although there may also be possible disadvantages and ethical dilemmas. These should be considered and weighted with respect to the particular context, specific needs and wishes of the person⁸⁴.

At some stage, it may be most appropriate for the person and the carer to move to more suitable housing; supported housing and extra care housing may prolong independence and enable the person with dementia to enjoy more time within their own community.

Who and how

An individual assessment is required to determine what may be appropriate in the particular circumstances; this should be carried out by an appropriately skilled practitioner.

The Dementia Practice Coordinator will be responsible for linking with the appropriate practitioner/s. This may include occupational therapy, physiotherapy, nursing and housing practitioners.

^{hh} The majority of people with dementia live in ordinary housing across all tenure types; the largest proportion are likely to be in owner occupied housing.

4.3.8 Pillar 8: Community connections

Description

Assisting people with dementia and their carers to maintain and build on their existing social networks and identify opportunities for peer support can enhance their quality of life. It can also maximise the natural support received from those around them. It can help people to attain and maintain maximum independence and have full inclusion and participation in all aspects of their life.

Why

People with dementia and their carers often lose social contact and can experience feelings of detachment from mainstream community life; this can increase their risk of isolation and result in greater reliance on care services.

What it will deliver

Remaining active and connected within the community will enable people to maintain their normal patterns of living and activities for as long as possible. Some people may require help to maintain their community connections and not withdraw from aspects of everyday life, whilst others may have already withdrawn and need support to reconnect. The right support can assist the person and their carer to identify the areas of their life that are most important to their well-being.

Peer support provides the opportunity for both the person with dementia and the carer to learn from those experiencing similar challenges. It can facilitate the development of coping strategies to reduce the impact of disabilities and maximise people's independence, self-esteem and wellbeing. It can also assist people to think about balancing independence with risk.

Who and how

The Dementia Practice Coordinator will work with the person and their carer to enable risk, plan purposeful community activity, maintain or regain connections and access peer support. They will also engage with community development partners and organisations to help people with dementia continue to use and be fully included in mainstream community activity.

4.4 Moving forward

The 8 Pillars Model provides each person with dementia and their carer with the best possible support to live in their own home. It intelligently combines health and social care to provide a fully coordinated response to addressing each aspect of the illness.

It promotes independence, citizenship and the right to participate as fully as possible in society. In addition, it will also avoid wasteful duplication by providing a structured joint health and social care practice approach.

The final section of this report provides recommendations on putting the model into practice.

5: Conclusion

The 8 Pillars Model of Community Support provides an integrated and comprehensive approach to the support of people with dementia and their families and carers. This will help to enable people with dementia to remain at home for as long as possible with moderate to severe dementia. At a time of demographic change, it delivers a coherent approach in response to increasing dementia prevalence.

This model builds on key developments in relation to post-diagnostic support and will ensure the impact of the investment in early intervention is not lost. It will also form an essential component of “transformational change to deliver world-class dementia care and treatment”⁸⁵.

By tackling the full range of factors that influence the experience of the illness in a coordinated way, it takes a therapeutic approach to enhancing the resilience of people with dementia and their families and carers: equipping and supporting them to cope with the symptoms of the moderate to severe stages of the illness.

The shift towards the integration of health and social care provides an ideal opportunity to transform dementia care in Scotland and to make it of a world-leading standard. The move towards community capacity building and proportionately fewer resources for institutional care requires a coordinated approach to support people with dementia in the community, which is provided by the 8 Pillars Model.

This model provides local authorities and NHS boards with a blueprint for restructuring integrated dementia care so that resources are used to greatest effect. Adopting this model must be a priority for the integration agenda; it will empower families, make effective use of the full range and depth of interventions, provide a coordinated approach to engage with all partners and use their resources and skills to the fullest effect.

5.1 Recommendations

- The 8 Pillars Model of Community Support should form a key priority area for the next **National Dementia Strategy** to be published in 2013.
- **The Scottish Government** should adopt the 8 Pillars Model of Community Support and ensure its implementation by making it a key target and outcome for the integration of health and social care.
- **Local authorities and NHS boards** should, as a priority, look carefully at the resources now spent on dementia care and realign their joint resources using the 8 Pillars Model, to deliver effective dementia care as part of the integration agenda.
- **Local authorities and NHS boards** should embed the Dementia Practice Coordinator role as a key component to ensure that every pillar of care and treatment is offered to each individual in a coordinated way to maximise the quality of life and resilience of people with dementia and their families and carers.

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Delivering Integrated Dementia Care: The 8 Pillars Model of Community Support

Dementia is a complex illness that impacts on the lives of 84,000 people in Scotland with the condition, and their families and carers. Effectively tackling the symptoms and consequences of the illness requires a coordinated range of health and social care interventions.

This report sets out an integrated and comprehensive, evidence-based approach to supporting people with dementia living at home. The 8 Pillars Model of Community Support for Dementia tackles the full range of factors that influence the experience of the illness.

Building on key developments in post-diagnostic support, the model will enhance the resilience of people with dementia and their carers during the moderate to severe stages of the illness. The 8 Pillars Model of Community Support provides local authorities and NHS boards with a blueprint for restructuring integrated dementia care.

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