The Fife Dementia Strategy: 2010 – 2020
Artwork featured on the front cover of the Strategy has been created by people with and affected by dementia in Fife.

Front cover artwork:
“Ainster”
Multi-medium Artwork
Created by the members of the Forward Centre, Glenrothes

This Strategy has been produced as part of a Knowledge Transfer Partnership between Fife Council, NHS Fife and the University of Stirling’s Dementia Services Development Centre.
Executive Summary

Dementia in Fife

The number of people living with dementia in Fife is set to increase dramatically over the next 20 years. This is due in part to an aging population, improved techniques to identify and diagnose dementia earlier than before, and lifestyle factors. Currently in Fife there is an estimated 5700 people with dementia. Approximately 63.5% of these people live in their own home in the community, while the remaining 36.5% live in long term care ¹.

Based on demographic predictions, by 2030 the number of people with dementia in Fife will nearly double and be an estimated 11000 people. Services must begin to adapt now to the increasing number of people with dementia and the shifting culture of care centred on the home and community. The current cost of health, social care and accommodation for people living in Fife with dementia is an estimated £88.6 million per year; by 2030 this will have increased to over £178.7 million per year at today’s prices.

Carers and people with dementia themselves are the experts in caring for and understanding the individual needs and preferences and must continue to play a vital role in ensuring a good quality of life. It has been estimated that the care and support carers provide is worth over £49.8 million per year in Fife alone.

The National and Local Context

The changing demographics of Scotland, the complexity of dementia and the impact it has on the individual and their family means that there has been an increase in the number of policies, guidance, and services being created surrounding older people and dementia. These mainly focus on joint working in an effort to provide services which meet the needs of the community, including people with dementia. A summary of each of the key policies can be found in Appendix 5. The Strategy has been designed to link into the aims and objectives of national and local agendas and initiatives including:

- Community Cares Outcome Framework
- Fife Health and Social Care Partnership Service Delivery Plan
- Living & Dying Well – Local Action Plan
- Fife Local Housing Strategy
- Scottish Government – Better Health, Better Care
- Fife Dementia Integrated Care Pathway
- Delivery Framework for Adult Rehabilitation
- Mental Health Collaborative
- Long Term Conditions Collaborative

¹ Alzheimer’s Society (2007). Dementia UK.
Locally in Fife there is also a lot of work being done which will improve services and support for people affected by dementia. An update is currently underway for the Fife Carers Strategy, and NHS Fife and Fife Council Social Work Service are working together to improve joint working for older people through the development of a Joint Commissioning Strategy. A local action plan to improve palliative care in Fife has been created in response to Living & Dying Well, the national action plan for palliative and end of life care in Scotland.

In Fife we are proud to be leading the way to improving and integrating services for people with dementia through the development of this Dementia Strategy.

**The Aims of the Strategy**

The overall aim of this Strategy is to ensure that significant improvements are made to services for people affected by dementia, and to ensure that in the future services have the capacity to cope with an increase in demand. The improvements can be made by investing in two main areas: our people and our services.

Throughout this Strategy 19 aims for improving the lives of and services for people affected by dementia are highlighted and are further broken down into a series of 41 recommendations and actions.

1) Improve collaborative working across health and social care services throughout Fife in order to improve the journey of people with dementia and their carers.

2) Improve awareness and knowledge of dementia in the general public and with professionals and practitioners in order to reduce stigma, improve rates of early diagnosis and ensure good dementia care is integral to all practice.

3) All individuals working with people with dementia have an appropriate level of dementia specific knowledge and skill.

4) Education and information materials and support are available for all people, regardless of location, and particularly for people with dementia and their carers.

5) All people with suspected dementia have equality in access to high quality assessment and diagnostic services which leads to appropriate and ongoing support.

6) Following a diagnosis, all people with dementia and their carers have equality in access to an assessment of their care and support needs.

7) People with dementia living in Fife have access to the best treatment delivered by highly skilled physicians in a consistent manner throughout Fife and have unrestricted access to information and research including strategies for the prevention of dementia.

8) People with dementia, their families and carers may require ongoing information and support following a diagnosis. Such ongoing support should be delivered by a knowledgeable professional, be offered to all individuals who receive a diagnosis of dementia, and be provided on an
individual basis whereby providers can develop a trusting relation with service users.

10) Support people with dementia to access housing options which meets their care and lifestyle needs including appropriate support to remain in the home of their choice.
11) To provide services and facilities which are designed to meet the needs of people with dementia and reduce the impact of the disability they experience.
12) Provide services for people with dementia in their own home which are responsive, flexible, consistent, and able to support their changing needs.
13) People with dementia have access to intermediate care services provided in a suitable environment and by well trained staff that are skilled in caring for and rehabilitating people with dementia.
14) To provide short breaks to people affected by dementia which are flexible, accessible and tailored to the needs of the individual.
15) People living with dementia in care homes receive quality care which meets their range of physical, emotional and psychological needs and preferences.
16) People with dementia who have medical needs requiring hospital care can be cared for in a suitable environment by well trained staff that are skilled in working with people with complex needs such as those of someone with dementia.
17) Emergency service providers are equipped with the skills and knowledge to effectively work with people with dementia, confusion or memory loss.
18) People with dementia and their families receive care that integrates a palliative approach as well good quality end of life care.
19) Ensure effective local support and leadership across Fife which will support the implementation of the Strategy.

The Strategy Outcomes

The Strategy will focus on achieving the following outcomes to improve the quality of life of people with dementia and their carers:

1) Increased collaborative working across all sectors and services who work with people affected by dementia.
2) Improved access to services
3) Increases flexibility of services
4) Services which are responsive to individual need
5) Improved continuity in care
6) Providing high-quality sustainable services
7) Increased staff knowledge and skill surrounding dementia
8) Increased awareness of dementia in the general public
9) Increased number of opportunities for carers and people with dementia to be involved in service development and provision
Implementation

The implementation of the Dementia Strategy will be led by the Fife Health and Social Care Partnership, supported by both the Mental Health and Older People’s Strategic Implementation Groups. A one year implementation plan has been developed in-line with the Strategy.

Within the Fife Dementia Strategy it is recommended that a lead is identified to drive the implementation of the Strategy and changes across Fife (See Section 3.1). The Lead will work to improve service coordination, knowledge sharing and integration and be supported by the work of the Older Peoples Strategic Implementation Group and the Mental Health Strategic Implementation Group, reporting to the Health and Social Care Partnership.

The Strategy has been designed to include a range of actions and improvements for change which will require various levels of financial investment. In order to be successful, commitment to implementing this Strategy will require some level of direct and in-direct investments in both people and services by the NHS and Council and other providers of care. However, as presented throughout the Strategy, the number of people with dementia in Fife is set to nearly double in the next 20 years and, without changes to the way services are developed and provided, the costs will exceed £280 million by 2030. By altering models and methods of service provision, and improving joint working and communication as recommended, we aim to provide high quality services which meet the needs of people with dementia and their carers in a more efficient and effective manner.
SECTION 1
Purpose & Scope of the Strategy

1.1 The purpose of the Strategy is to provide realistic and achievable recommendations supported by an implementation plan which will lead to service improvement and development over the next 10 years, and which will better meet the needs of people with dementia and their carers.

1.2 The Strategy is not written to provide detailed clinical guidance. Clinical guidance is provided through two documents produced by The Scottish Intercollegiate Guidance Network (SIGN)\(^2\), and the National Institute for Health and Clinical Excellence (NICE) in partnership with the Social Care Institute for Excellence (SCIE)\(^3\).

1.3 The Strategy is designed to be inclusive of all types of dementia in all groups affected including people under the age of 65. It has been written specifically for Fife, Scotland and has been developed in light of the local context and services available.

Understanding Dementia

1.4 Dementia is a generic term which is used to refer to a loss of intellectual and cognitive function including memory loss, significant deterioration in the ability to carry out day-to-day activities, and changes in social behaviour\(^4\). There are many different conditions which fit under the umbrella term of dementia. These include Alzheimer’s disease, vascular dementia, dementia with Lewy bodies and fronto-temporal lobe dementia. More than one of these conditions can be present in the same person, this is known as ‘mixed dementia’ and most often occurs with Alzheimer’s disease and vascular dementia. The causes of these conditions are generally not well understood, however research continues to uncover new information and is a valuable contributor to understanding the needs of people with dementia.

1.5 Dementia affects men and woman from all social and ethnic groups. The symptoms vary from person to person based on a number of factors which are not well understood. In addition to their dementia, individuals may develop other behavioural, psychological and physical symptoms and conditions which complicate their care. People with a learning disability are particularly at risk. The impact of dementia is felt by all, and this Strategy is designed to address the needs of all affected, particularly people with dementia and their family and carers.

\(^4\) SIGN (2006).
1.6 Carers of people with dementia and their families are profoundly affected by their caring responsibilities. Carers are often older and experience a high level of burden which may lead to depression, physical health issues and a decreased quality of life. However, carers can be any age with some people under the age of 18 caring for someone with dementia.

1.7 The impact of dementia is felt across the world and in Fife. The incidence (number of new cases per year) and prevalence (number of cases at any one time) rise exponentially with age. Currently there are approximately 5433 people 65 years and older and 316 people under the age of 65 living with dementia in Fife. According to general practice registers throughout Fife approximately one third of people with dementia have received a diagnosis. The aging population in Fife means that the number of people with dementia is going to increase significantly. The most recent estimates show that by 2030 the number of people with dementia in Fife will reach 11000.

1.8 In the years to come there will be an increase in the number of individuals with a learning disability and dementia as well as alcohol related dementia. Many of these people may be under the age of 65 and have unique needs which are rarely met by traditional older people’s services or services for people with a learning disability.

Figure 1. Demographic projections of the number of people with dementia in Fife

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1.9 Due to the complexity of the condition and a lack of relevant data, it is very difficult to accurately determine the costs of dementia in Fife. People with dementia commonly access a wide range of services provided by the NHS, Fife Council and a multitude of private and not-for-profit providers – and as they often do not have a diagnosis, they may be recorded as requiring services for a different reason.

1.10 However, Alzheimer Society in 2007 found that the average cost of caring for someone with dementia in the UK is £25,472 per year (including costs of health, social and informal care)\(^6\). The cost varies according to the level of progression of dementia, with further progressed cases requiring more intensive and complex care and thus costing more. The figure provided is an average of people at various stages of their illness.

1.11 Applying these figures to Fife means that the current cost of dementia in Fife is an estimated £138.4 million per year. By 2030 the annual cost of dementia in Fife will have increased to over £278.7 million at today’s prices.

1.12 Currently in the UK it is estimated that only one third of people receive a formal diagnosis of dementia, and that many people still believe there is nothing that can be done to help people with dementia. This is not the case. There are many things that can be done, and in order to ensure people are receiving the best care possible, services and the methods of provision need to be improved. This should be done in a way which will enable earlier diagnosis, and allow people with dementia and their carers to access quality support, treatment and care following a diagnosis. Without receiving a diagnosis people with dementia may be unable to access the most suitable support and services (social, psychological and pharmacological), and they may not have the opportunity to be involved in or make decisions about their future.

**Living with Dementia in Fife**

1.13 People with dementia in Fife may have access to a wide variety of high quality and innovative services aimed at meeting their individual needs. Many of these services are highlighted throughout this document in green ‘good practice boxes’\(^7\) and have been widely recognised for their innovation and the improvements they make to the lives of people with dementia. These boxes represent a range of services provided by Fife Council, NHS Fife and other organisations who contribute to improving the lives of people with dementia in Fife.

1.14 The accessibility and type of services available are based largely on the geographical area in which people live. Currently in Fife there are a multitude of divisions and boundaries which are used to differentiate

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\(^6\) Alzheimer’s Society (2007). *Dementia UK.*

\(^7\) For example see page 22 -The Fife Dementia Learning Forum.
and organise services and the population they serve. For example, NHS Fife is a single body with a number of organisational divisions including three Community Health Partnerships, a Mental Health service operating Fife Wide, Primary Care services which serve local communities across Fife, and an operational division with two acute hospitals located in Dunfermline and Kirkcaldy. Fife Council Social Work Services has two distinct boundaries separating it into East and West. It is felt by many frontline workers that the complexity of boundaries and the lack of organisational alignment between Health and Social Care complicates the provision of services and can negatively influence care.

1.15 The care needs highlighted above, and the complexities faced by current services providing care are compounded by the design and utilisation of communication and IT services within the NHS and Council. Currently the Mental Health and Acute Services operate unique information management systems from Primary Care and Social Work Services. Access to these systems is limited, service users are identified differently, and the systems often fail to communicate in a meaningful way.

**Figure 2a.** Fife Local Authority Boundary Maps.

**Figure 2b.** NHS Fife Community Health Partnership Boundary Map.

**Figure 2c.** Fife Council Social Work Service Boundary Map.
1.16 The Single Shared Assessment (SSA) was introduced in 2002 as a result of recommendations made in the Joint Futures Report. However, due to a number of reasons the SSA has largely been under continual development and change. Because of this, and due in part to its lack of fit-for-purpose for many health care workers and in part to the inability of NHS employees to input or access records created using the SSA, it has not functioned effectively. Currently very few providers outside of the Local Authority utilise the full SSA.

1.17 In this Strategy the focus will be on the unique lives of the individuals living with dementia and their carers in Fife. We recognise that the success of the Strategy is based on improving local services by re-focusing them on the needs of people, including those affected by dementia. The issues which are addressed in this document around the provision of care for people with dementia stems from the complexity of the condition itself and the individual corresponding need, and from the organisational complexities which impact services (see 1.14). For example, the development of a single shared care plan (4.7.2) and more integrated patient record systems (4.1.3) will go some way in improving communication across organisations, and ensuring all providers of care have access to information which meets their needs.

Developing the Strategy

1.18 The Fife Dementia Strategy was commissioned by Fife Council Social Work Services and NHS Fife through the Fife Health and Social Care Partnership, and has been created in partnership with the University of Stirling’s Dementia Services Development Centre. Following periods of research, information collection and consultation with a range of service providers and users, a Dementia Strategy Working Group was developed.

1.19 The multi-disciplinary and multi-agency 22 person Dementia Strategy Working Group used their expertise combined with research and good practice evidence to develop a series of recommendations. The Working Group met seven times, welcoming an additional 17 local experts over the course of the meetings and corresponded multiple times over email. The Dementia Strategy Working Group membership can be found in Appendix 3.

1.20 The development of the Fife Dementia Strategy has benefited from the contributions of service providers and users from across Fife. This occurred through two formal consultation events, as well as a series of informal individual and group discussions.


presented a range of information and evidence from a wide variety of research, reports, stakeholder input and recommendations by the multi-agency Dementia Strategy Working Group in the form of a draft Dementia Strategy. The Consultation Document invited all interested stakeholders in Fife to comment on the proposed recommendations, actions and outcomes, and to invite all interested parties to identify how each might be achieved.

1.22 The formal consultation took place over a 6 week period, and involved nine consultation events with service providers, users and carers. In total 97 written and verbal responses were received. The stories and ideas in many of the responses are highlighted in yellow boxes throughout the Strategy.

1.23 In general the draft strategy was very well received, and the recommendations identified were largely the right ones. Key areas where changes were made included: the important role primary care, other health professionals roles in the treatment and prevention of dementia (Section 4.2); raising awareness about dementia and the importance of a healthy lifestyle in prevention (Section 3 and 4.2); the importance of transport for older people and people with dementia (Section 4.7.5) and the provision of intermediate care for people with dementia (Section 4.10). These and other changes are discussed in more detail in the Fife Dementia Strategy Consultation Analysis report\(^9\).

The Strategy Structure

1.24 The Strategy is outcome focused, aimed at improving the quality of care available for people with potential or diagnosed dementia, and has been written for Fife with full consideration given to the local context. The Strategy is divided into two broad areas which form the basis for Sections 3 & 4 and contribute to:

- Improving awareness, knowledge and understanding of dementia in the general public and professionals throughout Fife, and
- Improving the care and services available for people affected by dementia in Fife.

1.25 Sections 3 & 4 are structured in a similar fashion, with the aim of each section supported by a series of recommendations which outline how each aim will be achieved. Each recommendation is supported by a brief case for change and is directly linked to a number of action points in the Implementation Plan. The Implementation Plan has been designed to include actions which are specific and measurable, and a timescale for implementation based on the priorities identified by service providers and users during the development of the Strategy. It is important that those responsible for implementing or facilitating change have a comprehensive understanding of the complexities

\(^9\) The Fife Dementia Strategy Consultation Analysis Report can be found online at www.socialwork.fife.gov.uk/dementia from the end of October 2009.
involved in providing tailored care to people with dementia, and have the abilities to influence services appropriately – the Strategy has highlighted leads for each action for consideration by the Health and Social Care Partnership who will oversee the implementation (See Section 5).

1.26 Section 4 focuses on services for people affected by dementia and has been written to correspond with how they are likely to be accessed throughout life. This was done to highlight the interdependencies services have, as well as any potential gaps or overlaps in services which may be improved upon. It is understood that people with dementia may not access services in the linear manner in which the strategy is structured, and that services and providers may respond differently based on individual need.

1.27 In addition to improving services, there are a number of improvements that the have been identified nationally and locally which the Strategy will contribute to. These are highlighted through various reports and policy documents which are summarised in Appendix 5.

1.28 Committing to the Strategy and its implementation will require a level of investment in people and in services. However, considering the current and potential costs of providing care for people with dementia in Fife (1.11), the aging population (1.7), and the impact failing to improve the delivery methods, focus and capacity may have, we cannot afford to delay. With an invest-to-save approach the Strategy aims to not only improve the lives of people affected by dementia, but to do so in a more financially effective and efficient manner.
Figure 3. Delivering the Fife Dementia Strategy to improve the lives of people with dementia and their carers.
SECTION 2
Vision for Dementia Services in Fife

2.1 This Strategy is designed to improve the lives of people affected by dementia by promoting the provision of high quality services and support in Fife which meet and are responsive to their unique needs. It aims to bring formal services together with individuals, communities and voluntary organisations to work in partnership to support people with dementia in Fife. The services will be accessible to everyone affected by dementia in Fife, regardless of location, and enable them to live as independently as possible in the environment of their choice. It invites people with dementia and their carers to be partners in care, giving them real choice and the ability to impact the care they receive.

2.2 In 10 years, using the aims highlighted throughout Sections 3 & 4, services for people affected by dementia in Fife will be:
   - Responsive to the needs of people with dementia and their carers;
   - Guided and developed through the use of individual budgets and self directed support;
   - Integrated into the community;
   - Operated through joint efforts across health, social care and housing providers;
   - Non-exclusive based on diagnosis and need;
   - Communicating effectively across and within services, as well as between service users and providers.

2.3 Dementia knowledge and awareness among clinical and non-clinical staff will be high as dementia education becomes an integral part of education programmes in Universities and Colleges and is a part of induction programmes in all local health and social care organisations.

Key Outcomes for Improving the Lives of People with Dementia in Fife

2.4 The key outcomes outlined below will be achieved through the implementation of this Strategy and the realisation of the aims highlighted above. The Implementation Plan provides a comprehensive list of how each aim contributes to achieving the outcomes below which are shown with key actions:

Outcome 1) *Increased collaborative working across all sectors and services who work with people affected by dementia.*
Collaborative working can be improved at all levels and across all services in Fife. Developing methods to facilitate improved communication such as a single care plan, an accessible electronic record system, and providing joint training and shared dementia resources will all contribute to this outcome.
Outcome 2) **Increased use of community groups and networks by people with dementia and their carers.**
Increasing dementia awareness in the general public and empowering people with dementia and their carers to build networks of support through their family, friends and communities will allow people to maintain independence for longer. The enhanced role of the community in supporting people living with dementia at home will be supported by services which are flexible, responsive, community based and better able to meet the needs of people with dementia and carers.

Outcome 3) **Improved access to services.**
Working together to clarify routes of referral and criteria for service use, developing direct access schemes for short break services, developing gradual and supported introductions to services, and ensuring appropriate needs assessments are complete will help to make services more accessible for people with dementia and their carers.

Outcome 4) **Increased flexibility of services.**
Developing extended hours and weekend delivery of day and overnight short breaks, improving access to community groups and services, and working with care providers to develop alternative models of care will all ensure services are more flexible and better able to meet the needs of people affected by dementia in Fife.

Outcome 5) **Increased services which are responsive to individual need.**
Services which are responsive to the individual needs of people with dementia are those which are provided by individuals and organisations who have a good level of knowledge and skill, are supported by their management, and have the resources to adapt services to individual needs.

Outcome 6) **Improved continuity in care.**
Aims and recommendations made in the Fife Dementia Strategy which will improve continuity in care include increasing communication between service providers as well as service providers and users; developing a single shared care plan which outlines care preferences and services; better integrating health and social care services, including intermediate care and care at home; and utilising the skills of workers across services.

Outcome 7) **Increased staff knowledge and skill surrounding dementia in all generalist and specialist staff.**
Increasing health and social care staff knowledge about dementia will be a key to the success of this Strategy. Methods for achieving this include developing new and utilising current expertise on dementia in Fife to produce and disseminate
dementia specific learning resources; improving access to educational resources; clarifying the role of specialist and non-specialist staff; and encouraging staff and service user involvement in service design and developments.

**Outcome 8) Increased awareness of dementia.**
In order to increase awareness about dementia and lifestyle factors people can control to prevent the onset of dementia general and targeted awareness raising campaign will be recommended throughout Fife aimed at improving understanding of dementia, how it affects individuals, contributory lifestyle factors and reducing stigma. Additional awareness raising activities will be carried out among health and social care professionals, including senior managers and will contribute to achieving this outcome.

**Outcome 9) Increased opportunities for carers and people with dementia to be involved in service development and provision with support from advocacy services where appropriate.**
The Strategy aims to achieve this through the implementation of a gradual and supported induction to support and services, regular and standardised opportunities for feedback, and a better understanding of services available for people affected by dementia. Service users and front line staff will be encouraged to participate in reviews of services conducted by the care commission, and to have greater role in deciding how services are delivered.
SECTION 3
Investing in our People

AIMS

Improve collaborative working across health and social care services throughout Fife in order to improve the journey of people with dementia and their carers. Increasing joint and integrated working will not only be an opportunity to improve communication and information sharing across services, but will also allow for the identification of service gaps and overlaps, and more continuous care.

Improve awareness and knowledge of dementia in the general public, professionals and practitioners in order to reduce stigma, improve rates of early diagnosis, promote the benefits of a healthy lifestyle, ensure good dementia care is delivered, and empower service users to develop individualised support structures. People living in Fife will have improved understanding of dementia and how they can reduce their risk of dementia which will assist in reducing stigma and improving diagnostic rates leading to earlier intervention and treatment.

All individuals working with people with dementia have an appropriate level of dementia specific knowledge and skill. As the population of Fife continues to age the number of older people and people with dementia will increase. In order to effectively provide and develop services which meet the needs of people with dementia, all those who work with adults and older people must have an appropriate level of dementia specific knowledge and skill, and are supported to deliver person-centred services at all levels.

Dementia education and information materials and support are available for all people of Fife, particularly people with dementia and their carers. People with dementia and their carers are the experts about their condition and should be provided with information and access to education and support services which can assist them in their role.

RECOMMENDATIONS TO ACHIEVE THIS

3.1 Appoint a Lead for Dementia in Fife who will play a key role in implementing the Dementia Strategy, and will work across health and social care services throughout Fife to increase collaborative working and service coordination.

Recommendations made below surrounding increasing awareness in the general public and in non-specialist clinicians will likely lead to an increase in the number of people being referred to specialist services for an assessment. Currently in Fife there are a variety of steps a person with dementia may take on their journey to receiving a diagnosis, these vary depending on a number of factors. Following a diagnosis people with dementia and their carers will
require a range of ongoing and short-term health and social care services based on their individual needs. The variability in the services and support accessed in the journey travelled while living with dementia is a result of the individual needs as well as the historical context and a lack of central and strategic guidance which has allowed the development of service gaps and perceived inequalities throughout Fife (see 1.14-1.18).

As the number of people with dementia in Fife continues to increase, services will be stretched even further, and without central leadership the links that remain may begin to pull apart. In order to improve equality and accessibility to diagnostic and ongoing support services, it is necessary that the service providers and users are involved in the developments which are led centrally. To ensure effective communication and information sharing a Lead for Dementia in Fife should be developed with a key role in improving service coordination and integration, and also in leading the implementation of this Strategy, working across health and social care services throughout Fife.

Many of the relationships formed during the development of this Strategy as well as the recommendations and actions identified in this Strategy will contribute to improving partnership working and collaboration. The Lead for Dementia will continue to maintain these links while fostering new ones.

3.2 Complete general and targeted awareness raising campaigns about dementia and the benefits of leading a healthy life.

Dementia is a condition which concerns society as a whole, yet continues to be associated with stigma and ignorance. This often leads to people who have dementia and their families withdrawing from social contexts and delaying seeking help or support in an effort to protect themselves and their loved ones.

There also continues to be a general belief in the public and amongst many professionals that following a diagnosis of dementia little can be done for the person with dementia or their family. This is not the case. Advances in treatments, interventions and services available for people with dementia have been shown to have positive effects including delaying the progression of symptoms, improving quality of life, improving understanding of the condition and enabling future planning, and reducing rates of institutionalisation.

By improving understanding about dementia, what it is, what can be done, and what benefits there are to receiving an early diagnosis, it is likely that more people will step up to acknowledge their condition and seek help. Awareness raising campaigns such as the initiative recently completed in Dundee using the Worried About Your Memory? material offers advice on what affects memory, how to help memory, what to do if you think you might have dementia and where to get help. By targeting advertisements to services and locations commonly used by older people, such as on the bus, on

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Alzheimer Scotland has recently designed information stations to be placed in buildings and facilities regularly visited by older people. Four stations have confirmed locations and another four are awaiting placement. The Stations are wall-mounted with a range of pockets featuring a variety of information on dementia for people with dementia, their carers and the general public. They also have contact details for Alzheimer Scotland Fife Service if people would like more information.

Learning from the above efforts, a local awareness campaign will be developed in partnership with Fife Council, NHS Fife and Alzheimer Scotland’s Fife Service which focuses on informing the public what dementia is and what it is not, the importance of healthy living, what to do if they suspect they or a loved one may have dementia, and what services and supports are available to them. It is anticipated that the National Dementia Strategy for Scotland will include national actions on awareness raising and informational campaigns, and in this case, in Fife we will ensure we integrate local and national campaigns in a harmonious way. Services must be developed in a coordinated fashion to ensure that any increase in awareness which may lead to increased demands on services is met by high quality services able to provide appropriate care and information.

Information campaigns will also be targeted at individuals who come into regular contact with the public and older people, informing them of how to

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recognise the symptoms and specific needs of people with dementia, how to communicate effectively with people with dementia, and what services are available to help should they have a concern. Groups such as receptionist staff, public transport providers, post office workers, pharmacy workers and older peoples groups are amongst those which will be included in targeted campaigns.

Campaigns targeting schools will be developed to promote inclusion, involvement and knowledge about health. Such efforts will also provide future benefits in reducing ageism, recognising dementia, and reducing negative stigma towards people with dementia.

3.3 Increased dementia awareness and skill among health and social care professionals and practitioners, including team leaders and managers who must support their staff to provide person centred care.

Fife Council and NHS Fife have both taken a proactive approach to developing workforce knowledge surrounding dementia care. Each organisation has funded a number of individuals to attend post-graduate and professional courses at the Dementia Services Development Centre at the University of Stirling and other providers. However, despite this positive shift in dementia learning and development not enough is being done to encourage knowledge transfer, leaving many staff working in services directly responsible for providing care and support to people with poor dementia awareness and skill. A lack of understanding of dementia and dementia services in Fife may lead to stigma, under diagnosis, under treatment, provision of inappropriate care/services and service users feeling as if they are being passed from pillar to post. Staff may struggle to understand and cope with the behavioural and cognitive symptoms of dementia which can be negatively reflected in their attitude and practices.

All staff in all organisations who work with adults and older people in Fife must be informed and educated in a manner which allows them to understand, effectively communicate, and provide a person-centred service for the person with dementia and their carers. As a minimum, dementia awareness should be included in all induction training for employees within the NHS, Council and partner organisations working with adults and older people, and more specific information and advanced training provided to those who provide care and services for older people or adults. Learning opportunities must be ongoing as a part of personal and professional development in Social Work, Health, Housing and Emergency Services. Research shows that opportunities for ongoing training and development for staff are linked with higher job commitment and employee retention, and that staff training on dementia care can affect their personal well-being.\(^\text{12}\)

All individuals and clinicians in Fife who may be responsible for identifying a

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potential case of dementia will be offered opportunities to increase their knowledge and skills necessary to recognise, assess and refer a person with suspected dementia; and where appropriate to manage and review people with a diagnosis of dementia. This will involve working with physicians throughout Fife as well as with Colleges and Universities to ensure health and social care workers are receiving dementia specific training. As part of this work a clear pathway for the referral of someone with dementia in Fife will be established and will include the point of recognition of potential dementia through to diagnosis and ongoing care (Section 4.2).

### Vision Loss & Dementia

Fife Council Older Peoples Service is working in partnership with the Fife Society for the Blind to improve awareness of people with vision loss and dementia in care homes throughout Fife. This innovative project will see specialists working with staff to improve their awareness, provide staff training, improve knowledge transfer, and develop more effective pathways for care delivery through joint working.

#### 3.4 Develop and improve access to dementia expertise and educational materials by utilising new technologies and methods, and ensuring they are available throughout Fife.

There are a number of new documents produced by various organisations which focus on improving knowledge and awareness of dementia in the general public and for people directly affected by dementia. Health Scotland’s *Coping with Dementia: A Handbook for Carers of People with Dementia* and *Facing Dementia: A Handbook for People with Dementia* are extremely useful resources, as is the general awareness leaflet by Health Scotland *Worried about your memory?* Unfortunately the use of these resources has been hindered by poor availability and accessibility.

In addition to such materials, in Fife there are a range of local dementia experts and services providing high quality and innovative services for people with dementia. Many of these are highlighted throughout the Strategy in the green Good Practice boxes. However, despite local expertise, there are two major factors affecting knowledge transfer and leading to many staff lacking the skill necessary to work successfully with people with dementia: 1) There are very few standard or organised ways to share information, and 2) Staff who work with people with dementia are under increasing pressures to provide services and do not have protected time for participating in or designing ways for knowledge transfer.

In order to develop staff knowledge and expertise and high quality services the Council and NHS must work with external providers to promote knowledge transfer and develop the role of local experts. This will include identified standards for information sharing after receiving professional training and will promote continual improvement. Service providers and care workers will work
together to develop and utilise current expertise on dementia within Fife to produce and disseminate dementia specific educational material to professionals and the general public. Such programmes will mean that resources are used more effectively, and that staff development opportunities have a more extensive impact and benefit for service users.

Internet and computer based resources provide an opportunity for information sharing and development programmes to be delivered to a wide audience at a relatively low cost. Such materials are easily accessible for many, and allow individuals to learn at a rate which is comfortable for them and fits into their schedule. The utilisation of such formats of training for dementia can allow individuals to participate in training and continue their personal development without the difficulties faced when trying to free up groups of people to attend training sessions, and should be a part of a package of resources developed for service providers and other people affected by or wanting to learn more about dementia in Fife.

The Fife Dementia Learning Forum

The Dementia Learning Forum hosted by Glenrothes and North East Fife, and Kirkcaldy and Levenmouth Local Management Units. It is a multidisciplinary event which focuses on information sharing and involves service providers, people with dementia and their carers. The events use a conversational approach to learning allowing carers and other local experts to share and learn from their experiences. The forums have become very popular, and booking requests often exceed capacity. To date topics have included working with people with dementia to develop life stories, legal considerations and the Adults with Incapacity (Scotland) Act, nutrition and dementia and end of life/palliative care.
SECTION 4
Investing in our Services

4.1 Assessment & Diagnosis

AIMS

All people with suspected dementia in Fife have equality in access to high quality assessment and diagnostic services which leads to appropriate and ongoing support. People in Fife with dementia have the right to access a pathway of care which leads them to a timely specialist assessment and accurate diagnosis which is communicated sensitively to the person with dementia and their carers, and which results in early support and intervention.

Following a diagnosis, all people with dementia and their carers have equality in access to an assessment of their care and support needs, and services which meet them. Services must be able to respond to the individual needs of people with dementia and their carers. Using a standardised assessment tool will ensure equality in access to services and will allow service providers to plan for future services which meet the needs of service users.

RECOMMENDATIONS TO ACHIEVE THIS

4.1.1 All primary care and social work staff understand the importance of and early diagnosis of dementia and a clear referral pathway for assessment and investigation.

In previous years research has shown that nearly half of cases of dementia have gone undiagnosed due to doubt surrounding the benefits that would come in realising a diagnosis of dementia and the lack of available resources. However, in recent years the value of receiving a diagnosis has become increasingly evident as changes in treatments available for people with dementia continue to develop and research demonstrating the benefits of early interventions continues to grow.

While efforts will continue to improve service providers’ dementia skills and knowledge as highlighted in Section 3, work must also ensure that the importance of receiving an early diagnosis is understood amongst all heath and social care providers. This understanding should be realised in conjunction with the knowledge and tools necessary to begin the service user down a clear referral pathway where they will undergo appropriate assessment and investigation by clinicians skilled in diagnosing dementia.

Following a diagnosis of dementia, individuals continue to receive high quality care and services guided by the development of a dementia patient pathway (see Section 4.2.1).

**I remember [my GP] being very very compassionate. He was very good that way, you know. And he explained the dementia, what effects it would have on me, you know. And he did say, “If ever you want to come and talk to me” you know, he was very good, “we’ll have a chat anytime you want to come.” (Person recently diagnosed with dementia)**

4.1.2 Develop the role of generalist and non-dementia specialist clinicians by ensuring clinical staff in primary and secondary care settings are able to recognise a potential case of dementia, rule out alternate explanations, and make an appropriate referral to specialist services for further assessment.

Local consultations completed within Fife show that it is generally the case that primary care and non-specialist physicians do not make a diagnosis of dementia; rather if they recognise potential cases of dementia they will refer their patient on to the appropriate specialist service. This practice is concordant with the rest of the UK. Non-specialist clinicians in secondary and acute care services play a similar role in this regard and face similar challenges in accessing specialist services and equipment necessary to make a dementia diagnosis.

There is a local concern that general awareness and recognition of dementia, as well as understanding of what to do if a patient is suspected of having a dementia in non-dementia/older person specialists, is limited. And, despite improvements being made in recognition, referral and diagnosis, the culture continues to be one of under diagnosis. Thus, as highlighted in Sections 3 and detailed in the Implementation Plan, an educational and awareness raising programme targeted at generalist/non-specialist clinicians will be developed. The targeted programme will be in line with SIGN guidelines to reinforce the importance in recognising dementia, making and effectively communicating an early diagnosis of dementia, developing skills in history taking for suspected dementia, and also ensuring awareness of follow-on services available for diagnosis and post-diagnosis support. This work will be completed in conjunction with the development of a clear referral pathway for assessment and investigation (4.1.1), and a continuing patient pathway (4.2.1).

The education programmes highlighted in Section 3 will lead to increases in the number of people with suspected dementia being referred to specialist services for assessments. As the SIGN dementia guidelines should be

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14 The term ‘non-specialist physicians’ refers to all physicians who would not normally make a differential diagnosis of dementia.
followed when making and disclosing a diagnosis of dementia, a high level of clinical expertise will be required. The involvement of specialist clinicians such as old age psychiatrists, neuroradiologists and clinical psychologists, and access to specialist equipment such as medical scans, will be required to make a differential diagnosis. It is thus necessary that there are an appropriate number of such professionals and equipment available for consultation in a timely fashion. In order to ensure this is the case a review of existing services, including waiting list times and time to diagnosis should be completed in an effort to highlight bottle necks and gaps. The review may then be used to ensure appropriate staffing levels are adhered to and there are no unnecessary delays. Similar models to those used in the diagnosis and treatment pathways in cancer care should be available to people with dementia.

Enhanced Assessment and Support Team (EAST)

In the North East of Fife, EAST provides a multidisciplinary approach in assessing and providing short term support for people with a diagnosis of dementia or other mental health illness. The team, which involves Health and Social Work employees (nursing staff, Occupational Therapy, Social Work and NHS support workers), provides an intensive, specialist needs assessment service for people with dementia in their own homes to avoid admission to a hospital environment. EAST maintains close links with a range of services to enable more holistic needs led solutions to individual cases. EAST only accepts referrals from the Consultant Psychiatrist for Older People in North East Fife. Central Fife has a similarly functioning specialised assessment team known as CAST which is not multidisciplinary (see page 65).

4.1.3 Create a virtual joined up care management system for people with dementia in Fife which is accessible to and utilised by clinical and social care providers.

Currently in Fife patient management systems used by social care, primary care, mental health services and hospital services use different patient coding characteristics and largely do not communicate or link up. This means that multiple separate records may exist for an individual, each potentially holding important information which is not being shared. As for all conditions, caring for people with dementia can be improved with a comprehensive understanding of the person and their life-history, sharing such records may lead to improvements in care.

In recent years a number of efforts have been made to improve the holistic nature of record keeping in Fife through initiatives such as the General Practice dementia register, the extension of NHS patient administration system OASIS to include the formerly separate Community and Mental Health Services, and perhaps most significantly the development of the Single Shared Assessment (SSA). These systems, some of which are still under
development, have gone some way in improving communication across services; however they continue face difficulties in ensuring continuity and consistency.

In order to ensure clinicians and care providers have the appropriate information to provide care and that information is being shared efficiently and effectively, it is recommended that a virtual care management system is created for people with a diagnosis of dementia in Fife. The system will be developed using existing tools and technologies, and will be appropriately accessible by all clinicians and care providers who diagnose or are involved in the care of people with dementia. Such systems have been successful in caring for people with diabetes in Fife and have functioned to:

- Facilitate information sharing.
- Prevent omission or duplication of services
- Allow audit of the service
- Provide a call/recall system
- Help identify unmet need
- Link with national screening programmes for associated conditions.

The virtual system will explore linking the SSA, with the GP Register, NHS OASIS system, and the new electronic Palliative Care Summary (ePCS). Individuals with dementia in Fife will be identified through existing general practice dementia registers and OASIS or as they receive a new diagnosis. People will be given the opportunity to opt into the sharing system in line with the Mental Incapacity Act.

Achieving the above will require not only organisational commitment and IT expertise, but will also mean that the SSA is re-worked in partnership with frontline health and social care workers and using the principles of good practice in dementia care. Financial investment will be required; however the success of the system will underpin the delivery of seamless clinical and social care services, and will play a key in future service and resource planning. It will also play an important part in managing the improvement to services made as a result of this Strategy and can be used to assist providers to follow appropriate diagnostic and care guidelines.

This system may also be used to develop an active research programme in Fife whereby people have access to relevant and up to date research information and are given the opportunity to participate in clinical trials and research of their choice.
4.2 Early & Ongoing Healthcare

AIM

People with dementia living in Fife have access to the best treatment delivered by highly skilled practitioners in a consistent manner throughout Fife.

RECOMMENDATIONS TO ACHIEVE THIS

4.2.1 Health and social care providers throughout Fife follow a clear patient pathway for people with dementia from the point of diagnosis which continues throughout their journey, and utilise a corresponding dementia learning pathway for skill development and information sharing.

Receiving a diagnosis of dementia is one step in a long journey of living with dementia which should lead into appropriate levels of support and treatment from a range of health and social care providers. As previously highlighted, throughout Fife there is a multitude of services people with dementia may access depending on a number of factors currently including their assessed levels of need, the area which they live in, and the referring practices of the service providers.

In Fife a dementia specific Integrated Care Pathway is being developed to act as a means of determining locally agreed multidisciplinary practice, recording variation from best practice and identify gaps in the care of an individual\(^\text{17}\). This dementia specific pathway will operate in conjunction with a generic Integrated Care Pathway to ensure a number of standards of care are met in the delivery of services to people with dementia in relation to their general health and their dementia. These standards have been established by NHS Quality Improvement Scotland\(^\text{18}\).

To ensure all people with dementia living in Fife have equal access to services which meet their individual needs it is necessary that a clear patient pathway is established, guiding service providers and users in their journey. The development of a patient pathway must be in-line with both the dementia-specific and generic Integrated Care Pathways, while focusing on meeting the needs of the individual through clear routes of referral.

In order to ensure continuous learning and improvement of services and individuals it is necessary to develop a Dementia Learning pathway which sits alongside the patient pathway. The learning pathway will have two key functions: 1) Facilitate continual improvement through a structured approach to learning and knowledge transfer; and 2) Provide service providers with a


detailed guide to disseminating information and sharing skills with people with dementia and their carers. Work currently being complete by Health Scotland surrounding improving information provision in dementia care is due to be complete in 2010 and should be used in the development of the learning pathway for Fife.

Developing the patient and learning pathways in-line with both the generic and dementia-specific Integrated Care Pathways will help to prevent duplication of work, allow for integrated evaluation, and ensure learning is taking place across all settings. Work on the Integrated Care Pathways is ongoing, and currently in Fife there is a need to focus on the applicability of the pathway for both health and social care providers in terms of how it will function as a holistic tool. For Integrated Care Pathways to effectively function ongoing work will be required in addition to current awareness raising sessions.

4.2.2 People with dementia receive appropriate treatment and care for their dementia and other health conditions from clinicians trained in their prescription, delivery and review.

Advances in the understanding of the changes or disturbances resulting from dementia have altered the management of patients with these disorders from a conservative, symptomatic approach to a more biologically and medically specific one. The mainstay of management is still based on the individual’s symptoms but the future promises the development of disease-specific and disease-modifying treatments which are currently only available in clinical trials. Recent attention in population health studies have also highlighted the importance of co-morbidity and frailty in the clinical picture resulting in a need for holistic patient centred treatment.

In order to ensure people with dementia in Fife are offered the best in treatment and care for their dementia and other health conditions a number of treatment and review procedures will need to be established. These have been broken down into those pertaining to dementia specifically, and those related to other health conditions.

A. Dementia specific treatments

Symptomatic (cognition enhancing) - Cholinesterase inhibitors should be openly available for all patients with a diagnosis of dementia and should be prescribed according to recommendations published in the SIGN guidelines19, depending on the dementia subtype. Treatment with this type of medication must be based on robust specialist assessment and diagnosis. Responsibility for initial prescription should be taken by the specialist making the diagnosis and thereafter be under joint review with primary care as advised in the Area and Drugs Committee Shared Care Protocol for Cholinesterase Inhibitors 200820.

Symptomatic (behavioural symptoms) - People with dementia who develop non-cognitive symptoms or behaviour that challenges should be offered a pharmacological intervention in the first instance only if they are severely distressed or there is an immediate risk of harm to the person or others. If this type of treatment is deemed necessary it should be introduced cautiously following recommendations laid out by Royal College of Psychiatrists (See Box above). The responsibility for review of this type of prescription in Fife is not currently clear, thus a consultation within NHS Fife must be complete with an aim to set out clear guidance for the shared responsibility of the regular review.

Particular attention must be paid to the use of such pharmacological interventions in care homes when used to manage the behavioural and psychological symptoms in residents with dementia. The recent report by the Care Commission and Mental Welfare Commission reviewing the care of people with dementia in care homes found that 75% of people were taking one or more psychoactive medicine and that 33% of people were taking antipsychotic medication\(^\text{21}\). These figures are much higher than would be expected, and are of particular concern due to the negative effects

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### Royal College of Psychiatry Recommendations on Treatment of Non-Cognitive Symptoms of Dementia

People with Alzheimer’s disease, vascular dementia, mixed dementias or Dementia with Lewy Bodies with severe non-cognitive symptoms (psychosis and/or agitated behaviour causing significant distress) may be offered treatment with an antipsychotic drug after the following conditions have been met.

- There should be a full discussion with the person with dementia and/or carers about the possible benefits and risks of treatment. In particular, cerebrovascular risk factors should be assessed and the possible increased risk of stroke/transient ischaemic attack and possible adverse effects on cognition discussed.
- Changes in cognition should be assessed and recorded at regular intervals. Alternative medication should be considered if necessary.
- Target symptoms should be identified, quantified and documented.
- Changes in target symptoms should be assessed and recorded at regular intervals. The effect of co-morbid conditions, such as depression, should be considered.
- The choice of antipsychotic should be made after an individual risk–benefit analysis.
- The dose should be low initially and then titrated upwards.
- Treatment should be time limited and regularly reviewed (every 3 months or according to clinical need).

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psychoactive medicines have been shown to have for many people with dementia, including the worsening of symptoms. In addition to guidance on reviewing medications, there is a development need for care staff and physicians in regard to using such treatments in people with dementia, and the important role that psychological interventions can have.

Psychological interventions for people with dementia have been shown to be effective ways to improve quality of life at earlier and later stages of the illness\textsuperscript{22}. The individualised nature of such approaches has meant that large randomised controlled trials are generally not appropriate, and thus evidence of their efficacy is often said to be lacking although anecdotal and small scale research evidence showing positive benefits is plentiful\textsuperscript{23}. Guidelines recommend that behavioural management approaches be pursued before considering the prescription of psychotropic medication\textsuperscript{24} but this is often not the case in practice. Psychological interventions to treat behavioural symptoms of dementia involve detailed analysis of a specific behaviour and the context in which it occurs. Triggers can then be identified which can be addressed or altered to reduce or eliminate the behaviour concerned. Such interventions can reduce distress in the person with dementia themselves as well as leading to greater understanding and enhanced skills in the carers and staff who work alongside the clinical psychologist or other appropriately skilled professional. Whilst interventions with individuals are important, changes to the regime in a whole care setting to support and facilitate a psychological approach are likely to lead to greatest benefit. This can include specific training in behavioural interventions leading to changes in staff attitudes and behaviour as well as changes to the physical and social environment.

**New treatments in development** - People who volunteer for clinical trials may gain access to promising drugs before these compounds are approved for the marketplace. As has been the case for cancer patients for many years’ patients with dementia should have the possibility to make informed decisions as to whether or not they would like to participate in ongoing clinical trials. A facility in which this can happen should be included in the development of the joined up care management system (See 4.1.3).

**B. General Health**

As approximately 50% of the population with dementia are over 85 years there is a need to consider the complex health needs and treatment of this part of the population, with dementia forming one part of what is known as the frailty syndrome (see definition of Frailty on page 31)

In order to ensure the medical needs of people with dementia are being met at all ages and stages of the condition their medical treatments need to be adapted in keeping with the severity of the frailty syndrome and other general health needs. In such cases of frailty joint GP and specialist input will be

\textsuperscript{22} For example see NICE Clinical Guideline 42: Dementia (2007).
\textsuperscript{23} SIGN 2006.
needed as the treatment of dementia cannot be viewed as a single health entity but rather as a part of a patient focused and coordinated health package of care and treatment. In cases where additional medical conditions exist, such as sensory impairment or physical disability, practitioners must work together to ensure person centred care is delivered in an integrated and coordinated manner.

Increasing knowledge and skill surrounding dementia will go some way in improving understanding of how dementia interacts with other conditions and impacts each individual, however there must also be clear routes for GPs to access specialist services such as Geriatric Medicine and Old Age Psychiatry when working with people with dementia (suspected or diagnosed) in Fife.

Frailty:
- Dependency (chronic limitations on activities of daily living with one or more functional, cognitive or social impairments)
- Vulnerability ("running on empty". An overall loss of physiological reserves and functional stability.)
- Co-morbidities
- Needs based rather than age based

4.2.3 People with dementia in Fife and the general public are informed about strategies for the prevention of dementia and have unrestricted access to information and research.

As highlighted in Section 3.2, people in Fife should be informed about the positive changes they can make to reduce the risk of having dementia in later years. With the majority of patients with dementia being over the age of 80 years innovative ways to prevent the symptoms of dementia should be sought in earlier retired life. Research on population health has shown key strategies may be used in the prevention of both Alzheimer’s disease and vascular dementia, and evidence from randomised controlled trials already exists for treatment of hypertension and prevention of dementia. These strategies may be divided into three areas: treatment of vascular risk factors, the protection of cells which comprise the nervous system, and increasing neuronal reserves through cognitive, physical and social activity.

The treatment of hypertension is well managed by primary care in Fife, however other preventive strategies should be introduced as newer research evidence becomes available. In order to ensure this is occurring older people in Fife should have unrestricted access to meaningful information on research and trials in the development of preventative interventions. This can be done primarily through the development of the dementia care management system (4.1.3), as well as through improving knowledge and awareness of clinicians (3.3), information and awareness raising campaigns (3.2), the development of

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online resources (3.3), and a single point of contact for information on dementia in Fife (3.4).
4.3 Dementia Advisors

AIM

People with dementia, their families and carers may require ongoing information and support following a diagnosis. Such ongoing support should be delivered by a knowledgeable professional, be offered to all individuals who receive a diagnosis of dementia, and be provided on an individual basis whereby providers can develop a trusting relation with service users.

RECOMMENDATIONS TO ACHIEVE THIS

4.3.1 Following improvements in dementia training, assessment and diagnosis, and based on evaluation results from similar local and national initiatives, consider the development of Dementia Advisors in Fife based on the Local Area Coordination model.

Research and consultation exercises in Fife have demonstrated that following a diagnosis of dementia, the person with dementia and their carer and family face a challenging road ahead, navigating services and coping with their prognosis. There are services to support people with dementia and their carers [For example: short break services (Section 4.9), care at home (Section 4.7) and the Alzheimer Scotland Early Stage Link Worker (pp 35)]; however, these are not consistently available across Fife, or are not accessed until later on in the journey with dementia. Depending on their diagnosis, prognosis, level of disability and support, people with dementia may not receive assistance or support directly following a diagnosis. There may be a delay of months or even years.

Many individuals have large community support networks which can be useful in supporting them through their diagnosis and assisting them to maintain normal activities and lifestyle. However many people with dementia and their carers have reported a lack of confidence in disclosing the diagnosis to friends and family for fear of rejection or misunderstanding. This, or a lack of understanding by family and friends may lead to a breakdown of support structures as the dementia progresses and changes become more pronounced.

Service users report not being aware of the services and information they can and often should be receiving, and report little in terms of emotional and educational support, finding it very difficult to ask for assistance. This is for a number of reasons, including that they may not be aware of what is available to help them, they are concerned that by asking for help they are admitting they are unable to cope, or they lack trust in service providers.

In order to improve the outlined situations, as well as ensure people with dementia and their carers receive the continuous support necessary, it is recommended that Dementia Advisors be considered to provide Fife-wide
services. This should be done once improvements to training, assessments and diagnostic processes have been made, and a the patient pathway (4.2.1) has been implemented.

The Dementia Advisor can function as a single and ongoing point of support and information in accordance with national guidelines by assisting individuals through signposting and empowering individuals to seek out information and develop local networks of support. They will ensure people with dementia and their carers receive information in a coordinated and effective manner using an information pathway (4.2.1). The Dementia Advisor will work with people affected by dementia directly following a diagnosis to empower them, providing them with the information and support.

The Dementia Advisor will work to increase the awareness and knowledge of local service providers, as there are many useful services available for people with dementia in Fife, however, knowledge of available services and how to access them is extremely variable. This is an important role for people with dementia and their carers who “experience referral to successive professionals and care settings, [leading to] insufficient clarity regarding professional roles in information giving”, and a lack of ongoing support. Although it is recognised that there is a role for such advisors now, there is a wide range of ongoing and new developments which will affect the potential role of Dementia Advisors in Fife.

At the time this Strategy was written Alzheimer Scotland was in the process of developing such a post in the North East of Fife, and may expand the service. In England a number of Dementia Advisor models are currently being trialled and will be evaluated in 2010/11. It is thus recommended that the immediate focus of work in Fife be given to staff training and development, and improving assessment and diagnostic processes as well as ongoing care as highlighted in the Implementation Plan. By focusing on such work initially it will not only allow Fife to learn from the experiences in England and by Alzheimer Scotland, but will also allow time for the careful consideration of how the Dementia Advisors will fit into the improved service models.

Because dementia is becoming so common we should be using community halls, that kind of thing. And get people up there a few times a week just to give carers a break – that would work a lot better than just these big day centres in another town... it maintains social skills too. (Dementia Care Worker)

They (social workers) basically get you kind of set up then drop the case, and that’s it. I understand why, being so busy, but it leaves you alone. My daughter deals with all that stuff for me. (Husband Carer)

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The details of the proposed post are listed in Appendix 4. The role of the Advisor is largely based on Local Area Coordination which promotes person-centred care, citizenship, empowerment, inclusion and support. Like Local Area Coordinator services, the Dementia Advisor is not provided based on need, and does not serve a primary assessment function (although some assessment may be necessary). The service fits well with other current agendas in dementia care including personalisation, self-directed support, supporting carers and the recent report on information provision.\textsuperscript{28}

In Fife, Local Area Coordination is already established within Adult Social Work Services. The service works alongside children and adults with learning or physical disabilities, autism, sensory impairments and attention deficit disorders. The most recent evaluation of Local Area Coordination has demonstrated its success in empowering individuals to access services and build support networks in the local community, to overcome barriers to participation and inclusion; to feel more comfortable, safe and independent within their own homes; and to have real choice and control in shaping their future decisions, and the confidence to act on these decisions. The service users who receive Local Area Coordinators support have also been shown to use mainstream social work services less, and Local Area Coordinators have supported community organisations to creatively think about how they can provide services for people with learning disabilities.

It is thus recommended that in 2012 the role of Dementia Advisors in Fife is reviewed. Changes in service models as a result of this Strategy, as well as the work of Alzheimer Scotland and the evaluation of English Dementia Advisors will be used to evaluate the need for Dementia Advisors in Fife, and to develop and implement a model which meets these needs.

\textbf{Alzheimer Scotland Early Stage Link Worker}

The Link Worker works across health and social care services, receiving referrals from Memory Clinics in Fife and offers preclinical support, as well as support during and after the diagnostic process. The Link Worker provides tailored information, advice and ongoing support to assist people through their journey with dementia.

\textsuperscript{28} NHS Quality Improvement Scotland (2009).
4.4 Supporting Carers

AIM

Implement the Fife Carers Strategy and the Fife Carers Information Strategy. Family carers are the experts and the most important resource available when it comes to caring for their loved one with dementia. Active work is required to ensure carer have the opportunity to be true partners in care, and also to ensure that these two Strategies which focus on supporting carers are implemented across Fife and that carers have access to appropriate support services.

RECOMMENDATIONS TO ACHIEVE THIS

4.4.1 Ensure that the needs of carers for people with dementia are included in the Carers Strategies and that these are implemented.

Carers of people with dementia face many challenges and play a very important role in providing support and care in the community. Each unpaid carer of a person with dementia saves the UK government on average £9170 per annum\textsuperscript{29}, and in 2009 the care and support provided by carers has been estimated at over £49.8 million per year in Fife alone.

Service providers throughout Fife need to recognise carers as partners in care, enabling them to fulfil their very important role. In order to ensure people with dementia and their carers receive the health and social supports necessary to remain independent for as long as possible, carers must be empowered to control the support they receive through a range of health, social care and community services. Creating new, innovative options to develop community support and networks (4.9.1) as well as improving transport solutions (4.7.5) will allow carers to develop unique packages of care. Self-directed support will be an important way for some carers to develop unique support packages.

In recognition of their contributions, and in order to improve the services and assistance they receive, there are a number of projects in Fife for carers in the community. NHS Fife published its Carers Information Strategy in 2008 which proposes a comprehensive action plan to assist carers in their role. The Carers Information Strategy will be linked to the Fife Carers Strategy, which is a joint NHS Fife and Fife Council Strategy currently under review.

Definition of a Carer: A carer is someone who looks after a partner, relative or friend who cannot manage without help because they are physically or mentally ill, frail or disabled. The carer and the person they care for may or may not live together.
In order to ensure that the Fife Carer’s Strategy and the Carer’s Information Strategy are effectively implemented they require support and commitment from all levels of staff in the Council, NHS and external providers. Consultations with service users and providers show that education and awareness raising about the vital role carers play in the community supporting older people and people with disabilities will be essential to the success of the Strategies. The Fife Dementia Strategy fully supports the aims of the Fife Carer’s Strategy and will support the Strategies by facilitating partnership working and promoting the role, recognition and involvement of carers in service developments.

My wife had Alzheimer’s. I looked after her for about 12 years. And it is a terrible job. She would remember her days when she was at school, and the old days, but what happened five minutes ago (shakes head as to indicate no). You used to have to watch her all the time, never let her out of your sight, she was very good at disappearing. (Carer)

I’ve only one worry, and I worry that I may be tiring [my husband] too much. You know. Mentally wise, you know. Because he is thinking about me all the time. He makes sure my medication’s there, he makes sure everything else that I would need is there for me. And [he’s] coming up for 80 and I have to think what would I do without him? You know. And I worry that the pressure that I’ve been putting on him is too much. (Person with dementia)

My mom went [to respite] to give my dad some time on his own because it was quite difficult. So, um, she didn’t always like to go, but when she got there it was a good experience – a god-send for the family. (Daughter of woman with dementia)

[My] disabilities applies pressure onto me with my other health problems and it does the same to your partner. If you’re out of the house, they get a break. (Service user with dementia)

4.4.2 Ensure that all carers are given the opportunity to complete a Carers Assessment, and that the appropriate services are available to meet the needs identified in the Assessment.

Of particular concern for many carers and service providers is the use of the Carers’ Assessment and the availability of corresponding support services. In 2007 it was predicted that only 1 in 1000 carers in Scotland had received an assessment\textsuperscript{30}, and that even when complete the assessment often failed to lead to the provision of services despite identified need. During consultations

\textsuperscript{29} Alzheimer Society (2007).
\textsuperscript{30} Carers’ Scotland Manifesto (2007).
with service providers and carers in Fife a number of reasons for the low rates of completion were identified:

- The Carers Assessment is not offered by the Service Provider. This may be for a number of reasons such as the service provider does not see or understand the benefits of the Carers Assessment due to a lack of education or due to experience whereby services are not available to meet identified needs, or the provider does not have time.
- Carer declines the assessment. This may be because the assessment was offered at an inappropriate time or in an inappropriate manner, the carer does not want to be assessed for fear they will be seen as ‘not coping’, or the carer does not understand the reason for the assessment.

In order to be an effective tool the Carers Assessments must be provided using a person centred approach. The reason for and benefits of the assessment must be fully explained and understood, and carers given the option to participate. The Carers Assessment should not be a one-off opportunity; the offer should stand, and be re-iterated when appropriate to ensure the carer has full rights and access to services and support.

Each person that cares for someone in the community has unique needs which should be assessed, met and reviewed using the Carers Assessment. This is particularly true for carers of people with dementia as the progressive nature of the condition means that not only with the needs of the individual with dementia change over time, so will the needs of the carer.

Following the Carers Assessment it is necessary that services are identified to meet the carer’s needs, and that these are accessible and appropriate as deemed by the carer. Consultations with service users and providers demonstrate that this is not currently the case and that often there is a lack of available support for carers.

Despite the lack of use of the Carers Assessment, it is accepted that the needs of the carers are considered during needs assessments and the development of care plans. However, it is not uncommon that the needs and wishes of the carer conflict with the person with dementia making it difficult to determine appropriate services and care pathways. In these cases it is essential that staff are able to communicate effectively with everyone involved, and where necessary ensure service users have access to relevant information and advocacy options.

Short break services are an important way of supporting people with dementia and their carers to remain in their home in the community. When a variety of models are available and are utilised properly they can offer benefits to both the person with dementia and the carer through the provision of a safe, person centred environment for the person with dementia while allowing the carer to take a break from the daily tasks involved in their role. Short break services should be considered as a model of anticipatory care as the benefits that do exist for people with dementia and their carers, including the prevention or delay of institutionalisation, are most likely to occur in those who
regularly participate\textsuperscript{31}. For a more in depth discussion on improving short break services for people with dementia and their carers see Section 4.9

\begin{quote}
[The Carers Assessment] could highlight whether the carer required further support from other support services. A disadvantage may be that there is often needs identified which our service cannot support, leaving the efforts in completing [the Assessment] a waste of time for carer. (Service Provider)
\end{quote}

4.5 Housing

AIM

Support people with dementia to access housing options which meets their care and lifestyle needs including appropriate support to remain in the home of their choice.

RECOMMENDATIONS TO ACHIEVE THIS

4.5.1 The housing needs of older people and people with dementia are identified in the Fife Council Specific Needs Housing Approach, and are given appropriate housing choices in Housing Options discussions.

The number of older people living in Fife is increasing at a dramatic rate, and with the shifting balance of care from institutional environments into the community, peoples’ homes are increasingly becoming the location for a range of support and care activities. It is thus important that houses are appropriately designed and equipped for the provision of care (for example bungalows without steps/stairs, bedrooms large enough for a bed to be turned, main floor bathroom facilities including showering, and wheelchair accessible doorways). This will present many challenges to the current housing situation as the care and support provided to older people if often linked to the accommodation lived in, rather than the needs of the individual. This is of concern, especially as the governments focus remains on providing affordable housing that is built to barrier-free standards. It is intended that such barrier-free housing will have the flexibility to be adapted to suit the needs of people with dementia; however resources and services for adaptation and other support for the specific needs of the aging population whose homes, new or old, may grow unsuitable as their physical and cognitive abilities change, are limited.

Age brings with it a greater acknowledgement of interdependence with family, community, services, and neighbourhood. To achieve the right balance between these means looking at planning for new homes and neighbourhoods which can sustain the changes of a lifetime; providing impartial information at an earlier stage so that people can make better informed and more confident decisions about a greater choice of quality housing options; have access to increased support to enable people either to stay in their own homes; or to move on.

To meet the challenges due to the aging population we must work across health, social care and housing services to plan for homes and communities that people can live out their lives in. People should be supported to remain independent, and feel safe in a community with their families and friends, and with accessible facilities around them for as long they wish to. We want to ensure that people are able to make the right choices at the right time with the right range of ‘specialist’ housing available for those who need more support including sheltered, very sheltered and extra care housing. Housing is central
to health and well-being, and services need to be planned and integrated to reflect this. These principles reflect what older people themselves have told us they want – above all, to be involved in determining what choices they must have.

In order to achieve this Fife Council’s Housing and Neighbourhood Services is currently updating the Housing Needs and Demands Assessment which mainstreams the needs of older people, including the needs of people with dementia. The resultant Specific Needs Housing Approach sits within the Local Housing Strategy and will function to improve housing options and access for older people through partnership working across other agencies, and through the education of housing staff about the special needs of older people, including people with dementia.

In addition to ensuring the needs of people with dementia are addressed in the Housing Needs and Demands Assessment, the Housing and Neighbourhood Services will work to develop a protocol to improve the Housing Options Advice for specific needs client groups including for older people and people with dementia. This will include a programme for increasing awareness of housing officers on the needs of people with dementia and individuals responsible for providing Housing Options interviews and information.

**I've got my own wee house, and that's where I like to be, in my own wee house. And even if it's not like it used to be, it's not as nice as it used to be and things like that, I still know it's mine and I can sit there if I want to, and watch television if I want to.** (Service user)

Service user: [In sheltered housing] there are not a lot of activities because there is only one person running it, well our place. And there is quite a lot to do for her. She puts lunches on on a Wednesday. Oh and we have a couple, we always have a couple of nights, get an entertainment night you know.

Day care worker: There used to be, the warden was based in the sheltered housing, and you maybe had two wardens in shifts and they were able to do more activities, but now

Service user (interrupts): Aye, we used to get help. It's like they, we're short of staff now and they cannæ do it.

**4.5.2 Improve joint working between housing providers, planners and developers and care providers to increase awareness of the needs of older people and people with dementia when it comes to building design, structure and support arrangements.**

In Scotland over 90% of people live in mainstream (or non-specialist) housing. It is thus evident that these mainstream houses need to be appropriately designed and planned in order to serve older people and future generations.
In order to ensure appropriate housing is available, housing providers, planners and developers will need to understand the unique needs of older people with physical or mental health conditions, including dementia. Such needs have been highlighted in the recommendations laid out in *Housing for Varying Needs* (Part 2, Section 1.5)\(^{32}\) and more recently in *Lifetime Homes, Lifetime Neighbourhoods*\(^{33}\). Following the update of the Housing Needs and Demands Assessment (4.5.1), the results and information will be used by the Asset & Facilities Management group in partnership with the Council Planning Department to ensure all new builds intended as social or rented housing meet the principles of dementia friendly designs and guidance laid out in *Housing for Varying Needs*\(^ {34}\) Part 2, Section 1.5, and all new houses intended for private use are encouraged to utilise these principles.

Within Fife there is a considerable estate of existing housing for older people and people who require support at home, however there is currently a lack of synchronised commissioning of accommodation, housing support services, and home care services to provide a holistic approach to meeting individual’s needs. There are cases where people have to turn down suitable accommodation because care packages cannot be put in place, and vice versa. Priorities of resources are different in different services and hence resulting in lack of understanding by providers and users whilst individual’s needs remain unmet. In order to develop a better understanding Fife Council’s Housing and Neighbourhood Services, as part of the Specific Needs Housing Approach, will develop a multi-agency Specific Needs Housing and Support Group to bring together joint working in the commissioning of accommodation, support and care services and will ensure that providers of housing and care will work together to determine how the housing needs of people with dementia will best be met.

Encouraging the development and provision of suitable housing options with appropriate support arrangements will allow Fife Council Housing Service to reconsider the capacity of current housing options and develop services which are appropriate for people with potentially high levels of need such as people with dementia. Examples of good practice in this area are already underway (See Fife Housing Demonstrator Project pp. 44) and it is intended that such projects will be learned from and developed into services throughout Fife.

Residents would often prefer to live in unsuitable conditions than to move, as moving can be a very stressful time. This is especially the case for people with dementia who often thrive on familiarity and consistency, and may find it difficult to adapt to new environments. The Fife Telecare Development Programme will continue to work across all housing sectors (home owners, private tenants, tenants of social housing) to raise awareness of the role of telecare to support people with dementia living at home and the role they can play in promoting independence, and to provide training for practitioners when making assessments and referrals for telecare services.

\(^{34}\) Scottish Homes (1999).
In addition, all staff from housing and housing support providers, including planners and developers within Fife will be included in the targeted awareness raising campaign and education programmes discussed in Section 3.

Fife Housing Demonstrator Project

The Health and Social Care Partnership endorsed the creation of a Demonstrator Project as a means of developing a strategic and operational framework around older people’s housing and related care and support services. Rosslyn Gardens in Kirkcaldy East was identified as a suitable site and multi-agency partnership meetings are ongoing to identify individual service needs and priorities with all parties in agreement that the site presents real opportunities to develop an appropriate project.

Delivering the Demonstrator Project is a key priority area for improvement in 2009/10 of the Specific Needs Housing Approach, through the Fife Housing Partnership, and presents Housing & Neighbourhood Services with an opportunity to develop an innovative model through the Strategic Housing Investment Plan (SHIP).
4.6 Design for Dementia

AIM

To provide services and facilities which are designed to meet the needs of people with dementia and do not increase the disability they experience. All new and refurbished buildings in Fife for use by older people or people with dementia are developed using the principles of dementia friendly design. Existing facilities which are not due for update are audited to determine the changes that can be made to increase their dementia friendliness. Such designs will also enable staff to provide higher quality services.

RECOMMENDATIONS TO ACHIEVE THIS

4.6.1 Ensure facility and service planners and developers are aware of the unique needs of people with dementia; and that they understand the importance of using dementia friendly principles in the design of public buildings and buildings that may be used by older people. This will include: housing, care homes, respite and day care facilities, health care facilities including hospitals and clinics, and other buildings for public use and particularly older people.

Research indicates that the using dementia design principles in a building can play an important role in supporting activities and positively impacting well-being\(^{35}\), and that poor design may negatively impact behaviour, promoting restlessness, anxiety and disorientation in people with dementia\(^ {36}\). The term ‘dementia friendly design’ refers to a wide array of structural and interior design features which do not hinder people with dementia by increasing their functional or psychological disabilities, and in fact can lead to improved quality of life. Where possible these features should be adapted to the needs and wishes of each individual and will commonly include\(^ {37}\):

- Utilisation of as much natural light as possible;
- Ensuring rooms are adequately lit;
- Using signage to assist in way-finding and preventing disorientation;
- Ensuring adequate toilet facilities are available, visible and sign-posted;
- In care homes using small units with a small number of people;
- Providing adequate space for those who like to walk to do so without encountering barriers or closed doors;
- Providing safe outdoor spaces where people with dementia can walk or sit and enjoy the smells, sites, sounds and various textures;

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\(^{37}\) Best Practice in Design for People with Dementia (2007). University of Stirling, Dementia Services Development Centre.
• Carefully selecting interior furnishings to reflect a home like environment;
• Selecting colours and flooring which are unlikely to increase impairment experienced by a person with dementia; and
• Utilising assistive technologies where possible.

There are a number of individuals working within NHS Fife and Fife Council who have undergone dementia design training at the DSDC, including four qualified dementia design auditors. These individuals will work with planners and developers to implement dementia design principles in all new housing and care (including health and social care), and certain commercial developments and public buildings through the building applications process. Designing new facilities using these principles does not have to cost more than when using traditional designs; however it does require specialist knowledge and planning.

Within and in addition to these principles of dementia friendly design, there are number of assistive technologies and telecare which can be used to enable people to live more independently for longer in any setting, and to assist in the management of risk (See Section 4.7.4). It is essential that new housing and facilities are developed utilising the principles of dementia friendly design which will enable to use of Telecare and assistive technologies at a later date without high cost and interruption. In order to do this the Telecare Development Programme Team will continue to work across all housing sectors to ensure facility and service planners and developers understand the importance and role of using dementia friendly principles and designing for potential future needs.

Individuals with dementia design training will also work with care staff to develop a learning resource which can be used in personal development and which educates them about the simple techniques they can employ to make the environment more dementia friendly.

Conversation with care staff working in a dementia friendly day centre:
Care Worker 1: One of the main things that I’ve seen… is in the kitchen. Care Worker 2: Everybody wants to help out now, and they’ve all got access to that. Everybody wants in, you know, they get up washing cups ‘n that… and that’s important to maintain their skills. They never used to do it [in the old facility].

Care Developments

Stratheden Hospital, Cupar, is the location for two new NHS Fife Old Age Psychiatry wards. One ward, named Elmview, opened in July 2009, and the second is due to be open in Spring 2010. Both were designed and built using dementia friendly design principles in consultation with the University of Stirling’s Dementia Services Development Centre.

Fife Council is also using dementia friendly design principles in designing a new care home in Kirkcaldy. The care home is part of the Council’s £40 million care home investment scheme and will be built in 2010/11.
4.7 Care at Home

AIM

Provide services for people with dementia in their own home which are flexible, consistent, and able to support their changing needs. This will include the provision of a range of services for care at home which recognise and are responsive to the individual needs and preferences of the person with dementia and their family. Communication between service providers and users will improve, as will the knowledge and skills of staff to care for people with dementia.

RECOMMENDATIONS TO ACHIEVE THIS

4.7.1 Develop alternate models of services for the delivery of care at home in partnership with other care providers which meet the demands of service users in regard to flexibility, reliability, and responsiveness.

Care at home services are the most used service by older people, and must be able to meet the specific and unique needs of a wide range of service users including people with dementia. People with dementia and their carers deserve to be able to control the services they receive, and services must be able to respond by offering them the appropriate level of support at the right time. Where appropriate service users and their carers should have access to control the services they receive through managing individual budgets, and where this is not appropriate they must be fully engaged in the development of the care plan and the provision of related services.

Care at home services must meet a variety of needs and range from providing access to transport, leisure opportunities, information, assistance in garden and domestic maintenance, and the provision of more intensive health and personal care. The needs of people with dementia will change as they live longer with their diagnosis and services must be able to respond to these changing needs, optimally without having to change provider or service each time needs change.

It is thought that often admission of a person with dementia into a care home is the result of an increase in need and a lack of available support at home leaving the carer unable to cope with the demands of the situation. It is at these points of crisis that carers often feel like “there is no other option”. A recent review of patients referred to the hospital discharge team found that a high proportion of those with dementia went on to live in a long term care facility. This is due in part to a lack of intensive support options at home.

The development of more flexible services with varying models of care may eliminate the need for unwanted moves into a care home, and may also be

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38 Hospital Social Work Discharge Team (Central Fife): Service Evaluatoin. (awaiting publication).
used to ease the transition into long term care if necessary. The provision of high-quality and flexible services may also positively impact the lives of people with dementia in many ways including: promoting and maintaining independence, supporting carers, reducing social isolation, and preventing admission to hospitals and care homes.\(^{39}\)

Currently care at home providers in Fife strive to offer a high quality service to people who have a range of needs, this include health and social care services. However, service providers face challenges in responding to the demand placed upon them as the number of people requiring support at home continues to increase; this is thought to be leading to the provision of task-focused home care which does not meet a number of the basic principles of care that people, especially those with dementia, need. Services must be able to work with and apply the principles of flexible person centred care integrated into a culture of skill maintenance and reablement.\(^{40}\) In the years to come there will be an increase in the number of individuals with a learning disability and dementia as well as alcohol related dementia. Many of these people may be under the age of 65 and have unique needs which are rarely met by traditional older persons care services or those for people with a learning disability. They require more flexible and adaptive services with staff that are skilled in working with people with such unique and often complex needs.

Care at home services must be comprehensive in their scope and able to provide the following:
- Carer and service user involvement in decision making processes;
- Staff who have dementia care training;
- Specialist staff with in-depth dementia care training;
- 24 hour intensive support;


\(^{40}\) Reablement refers to models of care which support the active process of regaining skills, confidence and independence. They are generally short-term services with intensive in-put.
• The support of assistive technologies and equipment (for example Telecare, handrails etc.);
• The ability to respond to emergency situations;
• Multidisciplinary involvement; and
• Regular reviews of care plans.

This will be achieved by developing specialist dementia home care teams within Fife Council home care service. The carers will have specialist dementia knowledge, and work with individuals to provide support and assistance, and to develop their dementia skills and knowledge.

In the long term Fife Council will investigate the potential to retarget its resources to provide specialist care at home services. These will include reablement services for all and specialist long term care teams, including one for people with dementia, which can provide intensive support 24 hours a day at home. Such services will offer a real alternative to allow people the opportunity to remain at home rather than moving into a care home. The Council will continue to work with external providers of care at home to develop high quality long term services for non-specialist care, and with community organisations to develop the opportunity for older people and people with dementia to participate in community groups and clubs (See Section 4.9.1).

My home carer is here today and gone tomorrow (pause) she just comes in and whish whoosh she is gone… she must have quite a few people. (Service user)

Home carers do not have a job they can time to the minute… Would I like it they suddenly said “Oh, wait a minute, I’ve got to be somewhere.” And were off? No I wouldn’t. So I’ve got no objection to them finishing the job there and [being late]. (Carer)

I’ve been in trouble on and off with homecare, you know, it never (pause) everything doesn’t seem to go right, you can’t get people to come in any old time. They want to be there for 10 minutes and they are supposed to be half an hour with you. But I’ve managed to sort most of it out anyways… you’ve got to insist that that is what I want and if you can’t provide this I don’t want anything else… you’ve got be a cut above otherwise you don’t get what you want. (Service user)

We know what we need, and we know when they get things wrong, but they don’t listen… people like us (service users) they should talk to, and carers and people like [him] (indicating to a carer) and my wife, that’s the people they should talk to, uh, because you get a better picture rather than making an assumption about us. (Service user with dementia)
4.7.2 Care at home providers regularly review and respond to the changing needs of service users with dementia, and that this is done using a multidisciplinary approach with a single, shared care plan.

Dementia is a progressive condition. For many people living with dementia care at home may be the primary or potentially only support delivered within the home environment. Care plans are a very important aspect of care at home services as they guide home care workers, and may also provide vital information for acute care staff and other health and social care professionals in an emergency situation. Regular and accurate reviews and updates, and easy accessibility are necessary to ensure that personalised services are being provided in an integrated fashion which meets the changing needs of the individual with dementia. Information must be communicated across services, and care routines and practices followed as closely as possible – people must not have multiple care plans with variable information. One care plan should be utilised and shared across all services the person uses with channels for sharing changes and updates well established and followed.

Currently for all services provided or commissioned by the Council, formal care plan reviews are to occur a minimum of every six months, with all external providers supplying the Council with updates of the review and notifying the Council to any alterations in the care plan (increased or decreased need). There are reported issues with the implementation and monitoring of the current system as changes in need and care plans are not always communicated to the appropriate bodies. A review is required to improve understanding of the current issues, and alternate models for information sharing should be considered to ensure equality in the assessment of need and allow for better regulation of external providers.

The content of care plans must include relevant information about the person with dementia, including their personal preferences and needs, and a brief life history, including their past residences and the contact details of family and friends. This was identified as being of high importance by the Police and other services during an emergency situation, especially when a person with dementia becomes lost or disorientated as they may attempt to return to these locations. It is also necessary that the care plan is located in an easily identifiable and accessible location, and that this location is the same for all individuals receiving support at home.

The single care plan will be used across services in organisations to improve continuity in care. And, while it is recognised that some information may not be shared due to data protection, the single care plan will act as the basis for coordinating care delivery.
4.7.3 Improve joint working and communication within and between providers and regulators of care at home services across Fife in order to ensure quality services are being provided in a coordinated and effective manner.

In order to improve services efforts must be made to reduce fragmentation, and improve communication and joint working between the Council and other local providers of care at home. By establishing better and more consistent methods of communication the Council and NHS can work alongside private and third sector providers to ensure the needs of people with dementia are being met.

Training and development provided for care at home workers vary significantly by organisation, and the same is true in regard to dementia-specific knowledge. Many service providers feel that financial and time constraints limit their abilities to provide the level of training they would like to, and that this negatively impacts the quality of service provided. This is despite evident that suggests investing in and educating staff can improve staff morale, reduce turnover, reduce future adverse incidents and lead to financial savings.

It is proposed that a Home Care Delivery Group for all services providing care at home in Fife will be established and organised by Fife Council on behalf of the Health and Social Care Partnership. The chair of the group will alternate between services involved, and the Group will focus on discussing issues and good practice surrounding standards of care, care planning, ensuring services are coordinated and actively communicating, and addressing the particular issues of specialist dementia care. One of the issues the group will address is how care at home staff can be more involved in Care Commission reviews to ensure more dialogue between employees and Care Commission occurs. This will be done to ensure a more accurate review, and also to improve the relationship between the Care Commission and providers to encourage alliance and learning.

In order to improve the standard of training care at home workers receive the Council and NHS will work in partnership with other providers in Fife through the Home Care Delivery Group to develop and implement a standardised training programme. NHS Fife and Fife Council have a unique position to other care providers as they can work to improve services through their commissioning methods and standards as well as through knowledge transfer. In an effort to improve the quality of care provided at home throughout Fife, the Council will continue to work with commissioned services to review standards for commissioning care at home, and ensure they are aligned with the key elements of care as indicated by service users – reliability, flexibility, continuity, communication, trustworthiness, staff knowledge, and skills and attitude\(^\text{41}\). The criteria for selection which are based on these key elements of care will involve minimum training standards with dementia specific elements and standards to ensure commitment to

continual improvement and joint working. The measures must be easily recordable, and reporting will be a requirement for all services commissioned and provided by Fife Council and NHS Fife. A response system for dealing with under-performance will be designed to support service improvement.

By altering current commissioning requirements to focus more on meeting service user needs and improving joint working and continual improvement, and working with local providers to achieve high quality services, the Council and NHS can play a proactive role in improving the care received by all service users, including people with dementia.

**Fife Telecare Development Programme**

The Fife Telecare Development Programme provided telecare services for people with dementia. Telecare systems of particular relevance to dementia include: door exit monitoring systems and motion detectors to reduce the risks of nocturnal wandering; home safety equipment to reduce risks of fire, gas, flood, carbon monoxide and low temperature; and falls detection and prevention. Innovations in lifestyle monitoring, GPS tracking for safer walking and the use of medication dispensers to improve compliance with prescribed medication are being evaluated during 2009/10.

### 4.7.4 Continue to develop assistive and telecare technologies to support people with dementia in their homes.

Telecare technologies have been used for years in Fife, primarily in the form of the Community Alarm, and recent advances may provide numerous benefits for people with dementia in their own home. The continued use of such technologies may present a cost-effective method for promoting the independence of people with dementia in the community without regular disturbance by care staff. When commissioned Telecare technologies can successfully alert relatives or care staff to an issue so that they can then proceed with initiating an appropriate response.

The role of assistive technology and telecare in Fife and for people with dementia is growing as advances continue to be made in the development and application of technology. In order to ensure people with dementia are receiving appropriate care and services, the Telecare Development Team will work to further investigate the technologies available to assist people with dementia living in the community in partnership with care at home services.

Additionally, as highlighted in Section 4.5.2 and Section 4.6.1, The Fife Telecare Development Programme will work across all housing sectors and the Home Care Delivery Group (4.7.3) to raise awareness of the role of telecare to support people with dementia living at home and provide training for practitioners when making assessments and referrals for telecare services.
4.7.5 Ensure older people and people with dementia have access to transport which is suited to their physical needs and lifestyle preferences.

In Fife, much like other local authorities in Scotland, public transport is an essential way for individuals who hold a concession (i.e. over the age of 60 or living with a disability) to get around. For most this is achieved through the use of public buses, however for those with greater need additional supported transport options exist (for example Social Work Service operated transport; or Council local concessionary travel schemes such as Taxi Cards, Dial-a-Ride and Ring-n-Ride\(^{42}\)). Continuous improvement is important to many transport providers throughout Fife in order to enhance the role transport plays across all user groups, and it is important that people with dementia are included in consultation processes with stakeholders.

In addition to Council operated services, throughout Fife there are a number of local initiatives set up to improve transport options for older people in the local community. Unfortunately, the lack of awareness by potential users of many of these projects highlights the need to better communicate such schemes. Throughout consultations for the Dementia Strategy, service users, including people with dementia and care providers, identified transport as a significant issue affecting the ability to live an independent life and utilise local services and facilities. This was especially true in the more rural areas of Fife, particularly in the North East, where there are limited public transport options available.

Many of the service users who took part in the public consultation reported using short break services such as day care as they had no other opportunity to socialise due to difficulty in accessing transport. Often aware of potential groups and events they would like to attend in their local community, many older people were unable to do so as they lacked transport options and were unable to use public transport alone and unsupported. As day care services provided by the Council has its own supported transport attached this is the

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\(^{42}\) Details of Concessionary Travel Schemes in Fife are available on www.FifeDirect.org.uk then click on > Travel & Transport > Public Transport > Concessionary Travel.
option of choice for many, and often necessary to prevent social isolation. While it is acknowledged that many service users in day care have complex needs which are suitably met by the service, there are others who may be attending due only to social isolation. In these cases other, less intensive services may be appropriate if only the necessary transport arrangements were in place.

As indicated previously, transport arrangements to and from Fife Council Day Care Services are provided by a varying degree of accessible mini-buses and people carriers owned and operated by the Council. Following transport from home into the day care which is generally complete around 10am, it is understood that many of the vehicles remain parked at the care facility or used intermittently until they are needed to take service users home around 3pm. On some occasions the vehicles may be used by other services such as residential care, or out in the community, however this is inconsistently practiced and not the part of routine working arrangements. There appeared to be a number of barriers preventing more flexible use including a lack of qualified drivers and how to effectively overcome these is not wholly understood. In order to optimise transport options for individuals remaining in the community and in residential care, transport vehicles should be used throughout the day for activities such as taking those living in care homes out, or taking individuals living in the community to activities, lunch groups or other services. Developing a programme to achieve such arrangements will require involvement of both Transportation and Social Work Services, and the involvement of local community services/groups.

In order to guard against social isolation and ensure older people are being provided services which are appropriate to their level of need it is necessary that all social care services operate their service owned transport as efficiently as possible. Guidance at a national level would support this work and perhaps enable the development of appropriate procurement partnerships to allow social care services to extend its transport provision.

Local consultations with older people and people with dementia completed for the Fife Dementia Strategy found they were apprehensive to use public transport due to the inconvenience of having to plan a schedule around the bus, lack of flexibility in terms of timing, walk distance to and from the bus stop, and safety while on or waiting for the bus. These are in line with concerns raised in a recent consultation conducted by Fife Council Transportation Services. In order to address these concerns, as well as to ensure optimal use of existing transportation vehicles, Fife Council Transportation Service has been asked to undertake a review of community transport provision in Fife. The review will be completed in partnership with Social Work Services and various other groups, and consider a range of issues and services available in Fife. A brief for this is currently being drafted.

While the review process is ongoing social care providers can facilitate access to concessionary travel and supported transport options through the utilisation of the Single Shared Assessment, and also through promoting the use of appropriate local transport solutions available in their area.
Fife Council Supported Transport Services

Fife Council currently provides a range of transport services throughout Fife both internally and through external contracts. The Ring & Ride and Dial-A-Ride services are operated in various regions throughout Fife and are intended for use by people who find it difficult to use normal bus services. Each of the services provide a varying degree of accessible vehicles and service users are picked up from their door, assisted to the vehicle and dropped off at the arranged location. The Ring & Ride service operates from 8.30am to 10pm seven days a week within four geographic areas, is bookable one day in advance and will transport individuals to any location within the defined area. The Dial A Ride service is an accessible shopping service which picks up service users from their home and transports them as a group to a nearby shopping centre. The service operates Monday – Friday and is bookable up to two weeks in advance.
4.8 Intermediate Care

AIM

People with dementia have access to intermediate care services provided in a suitable environment and by well trained staff who are skilled in caring for and rehabilitating people with dementia. Both generalist and specialist intermediate care services are available for people with dementia in order to prevent unnecessary admission to hospital and facilitate discharge.

RECOMMENDATIONS TO ACHIEVE THIS

4.8.1 General intermediate care services are run by well trained staff and have clear, consistent and well communicated pathways for referral and criteria for access and use, including for people with dementia.

Intermediate Care refers to any service whose main aim is to prevent unnecessary admission into, or support discharge from, a hospital setting back into the community. A recent report on generalist NHS intermediate care services in Fife found that “people affected by dementia make up a considerable proportion of the clients seen by teams and services providing support to prevent unnecessary admission and support discharge from hospital”\(^{43}\). In Fife there are a range of services which provide intermediate care, although these are not always easily accessible, especially to those who work with patients with mental health or cognitive issues such as dementia.

In the aforementioned report, some inquiries were made into the eligibility criteria for people affected by dementia. The researchers reported an overwhelming response that there were no separate criteria for people with confusion or memory loss such as is experienced in dementia, and that if it was thought the service user would benefit from that team’s input, they would be accepted to that service\(^{44}\). However, as the main aim of intermediate care services is to assist people to get back to the level of independence they previously had, and in some instances this is not possible with people with progressed dementia due to the progressive nature of their condition, generalist intermediate care services may not always be appropriate.

Consultation work done during the preparation of this Strategy demonstrated that there was some confusion over referral criteria for service use by people with dementia as clients were not being accepted for reasons not understood by the referring provider. And, whilst it is understandable that each decision must be made individually based on a number of factors, it is necessary that an individual who is denied a service understands why this was the case and


\(^{44}\) Ibid.
is referred on to a more appropriate service. There are concerns over these inconsistent approaches and the impact they have on the service users.

In order to ensure equality in access as well as efficient referral practices, all intermediate care services in Fife must review their referral criteria, ensuring all relevant service providers are aware of the criteria and why the criteria exist in the form they do. Where necessary intermediate care services should re-develop their criteria, ensuring they are clear and implemented consistently across the service. This will include criteria for use by people with cognitive impairments such as with people with dementia, and in instances where it is decided a person will not benefit from the service they will be referred to a more appropriate service such as a specialist team (see Section 4.10.2). The review process has already begun, with Fife Council working in partnership with NHS Fife and the Mental Health Collaborative, and with Integrated Response Teams (generalist intermediate care services) to identify ways of improved working with people with dementia. Intermediate care services will be included in the development of the dementia patient pathway as described in section 4.2.1.

If it is the case that intermediate care services are being provided for people with dementia then the services need to be structured in an appropriate way which supports the individual needs of someone with confusion/memory loss. As many services are currently not targeted at this group providers may not have received the appropriate level of training. The report on generalist intermediate care services drew attention to this point: “It was highlighted that the training needs of staff should be considered to ensure team members were appropriately trained in working with people affected with dementia.”

In order to ensure the people with dementia are receiving an intermediate care service which meets their needs, all generalist intermediate care staff working with adults and older people must receive dementia specific training.

### 4.8.2 Develop specialist mental health intermediate care services which are available across Fife and have clear, consistent and well communicated referral criteria.

The options for an older person when they cease (temporarily or permanently) to be able to live independently at home are often limited due to the speed of onset of this scenario and a lack of flexibility and responsiveness in current care services. In many cases the default action for this situation is for an individual to be admitted to an acute hospital.

As discussed in section 4.11, acute hospitals are a particularly challenging and stressful environment for people with cognitive or communication impairments such as those present in many patients with dementia. In general people with dementia in hospital in general have worse outcomes in terms of length of stay, institutionalisation and mortality.

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There are few specialist intermediate care services for people with dementia operating in Fife (e.g. EAST, CAST, Old Age Psychiatry Liaison Service), and due to historical and financial barriers, access is geographically restricted and, unlike generalist intermediate care, they have not been subject to a comprehensive review. At the time of evaluation of generalist intermediate care services it was felt that this topic merited a dedicated piece of work on its own which has yet to be completed. Service providers feel that a lack of appropriate services available throughout Fife is likely contributing to inappropriate admissions into hospital, delays in discharge from hospital, and unnecessary moves into care homes.

In order to develop a comprehensive understanding of current specialist intermediate care services in Fife for people with confusion/memory problems, and to identify gaps in services and modes for future development, a review is necessary. This review should include an evaluation of how/if these are accessed by people with confusion or memory problems such as those present in people with dementia, in an effort to differentiate rhetorical criteria from actual use.

In the short term it is necessary to develop referral criteria for specialist intermediate care services which are explicit and clear in regards to access and referral pathways to alternate services which meet the needs of people with confusion or memory loss. This work will also be used to inform the development of the patient pathway described in section 4.2.1.

In the longer term, the information collected during the review of specialist services will be used to identify and develop alternate models of care which will be accessible throughout Fife. Particular attention should be given to the role of intermediate care services in admission prevention which provides the greatest impact on quality of life\textsuperscript{47}, and improving joint working between hospitals, intermediate care services and care at home providers.

\begin{center}
\textbf{Central Assessment & Support Team}
\end{center}

CAST is a specialist mental health nursing assessment team and is part of the Mental Health Service for Older People. The team currently takes referrals from the Levenmouth area and a limited number of Kirkcaldy practices. It provides short-term, home-based assessment, treatment and support for patients over the age of 65 with mental health difficulties including dementia who have related problems of a complex nature and for younger patients with an established diagnosis of dementia. Assessment is carried out promptly and flexibly with visits planned according to the needs of the individual patient. The team works closely with catchment area psychiatrists and other members of the multi-disciplinary mental health team. Support is transferred as soon as possible to longer term care providers.

4.9 Short Breaks

AIM

Provide short breaks to people affected by dementia which are flexible, accessible and tailored to the needs of the individual. Services must include a wide range of short break options which are responsive to the needs and preferences of the person with dementia and their carer, and are accessible for all people living in Fife including those affected by dementia.

RECOMMENDATIONS TO ACHIEVE THIS

4.9.1 Develop the provision of short break services which meet the needs of service users in regard to flexibility, accessibility, activity and focus.

Traditional models of short breaks through either day or overnight care provided in an institutional setting are still the predominant model of care provision in Fife. This is likely the result of the still common view of short break services being provided to relieve the main carer of their duties for a temporary period. Although this is important, short break services must also be recognised as an opportunity to improve the life of the person with dementia through increased activity, and high quality care.

In order to develop more flexible and community centred models of short breaks it is recommended that Fife Council Older People’s Service work with the Adults Service Resource Team to develop and pilot alternate models of community based short breaks for older people, including people with dementia. In the Adults Service Resource Team carers are recruited through community advertisement and offered the opportunity to provide day, overnight or long term care within their own home. If, after extensive interviews, training and assessment they are suitable for the role, they are individually matched by a Social Worker with a service user who maintains regular contact with both the service user and care worker. The service has been developed in-line with the National Care Standards, has been very successful in the matches it has made, and service managers report positive feedback from all those involved.

Currently service users are left with little choice in terms of short break options, and people with dementia are often more greatly restricted as they may be prematurely labelled as unsuitable for a service due to their condition. In some areas of Fife short break services are over-subscribed and individuals are placed on a waiting list until a place opens up. The wait can vary significantly from a matter of weeks to months or even a year. In an effort to improve ease of access to short break services a direct access scheme has been successfully piloted in the West of Fife, whereby service users and carers can access Fife Council day care services by self-referring to the local authority. The evaluation of the pilot is near conclusion and it is due to be rolled out across Fife.
Research and consultations with service users show that often the most challenging parts of the day for carers of people with dementia is the early morning/breakfast period and the late evening/supper period, and that often the reason a carer is requesting a break is to attend an activity or event which may be in the evening or on the weekend. These are all periods not covered by a standard short day break service whereby individuals are commonly picked up at 9-10am and returned home from 3-4pm, leaving the bulk of the caring activities to the carer at home. Thus, in addition to direct access, and in an effort to ease the burden of care on family carers, short break services provided by the Council will be developed using more flexible models of provision such as on weekends and in the evenings, and offer greater flexibility in duration and location. Private providers of short break services will be supported to develop similar models. In support of this goal an increase in the availability of respite monies in Fife is currently being used to extend flexible short break services for people with dementia which are highly adaptable and responsive to the needs of the service user.

In addition to traditional models of short breaks provided in large groups in centres as well as community based short break services discussed previously, older people and people with dementia will be encouraged to utilise local community groups and clubs. Such groups could play an important role in preventing social isolation of both the person with dementia and their carer, and are available in a wide variety of locations, unique in duration and covering a range of topics. Dementia Advisors and other health and social care providers will play a key role in facilitating the use of community clubs and groups, and transport is a key to the successful utilisation. For a discussion on transport see Section 4.7.5.

As well as greater flexibility, a review will be done on improving the continuity of care through coordination of day services and overnight services. Wherever possible people will be offered overnight care in the same location of their day care, and staff will be expected to transition between the two to help people with dementia adjust to their new environment.

Research shows that services targeted to people under 65 with dementia often have additional activity options available including activities away from the care centre, and improved transport arrangements to make the outings a reality. Such options are not equally available to older people, and there is no evidence to support or contrast the reason for such arrangements. This is the case in Fife where a specialist short break service for people under the age of 65 with dementia has one staff for every three people with dementia, compared to short break services for people over 65 where there is generally one staff for every five to six service users.

There are alternate opportunities available for people affected by dementia in Fife including short break services which are based in the home and community of the service user often on a one to one basis. This model of care is useful; however there are additional ways to deliver flexible services which should be adapted for use with older people and people with dementia. For
example, many services provided for people with learning disabilities may be useful for people with dementia, including developing small circles of care with volunteers in the local community. Rehabilitation and reablement are also possible features of short break services. Fife Council and NHS Fife must work in partnership with independent providers to explore and develop a spectrum of such models of care which can be stepped up or stepped down based on the individual needs of service users.

In order to provide proper care, activities and programmes must be built around the individual. Activities completed in day and overnight care must be suitable and stimulating for all service users, including people with dementia, and satisfy their social, cultural, religious and recreational interests and needs. Research has shown that activities that centre around the person’s normal daily life and events, such as preparing a meal, and visiting a local shop or a familiar sight, improves the service users quality of life, affecting mortality, depression, physical function and behavioural symptoms for people with dementia, and improving self esteem and sense of identity\(^48\).

Much like the case highlighted in the recent report Remember, I’m Still Me\(^49\), activities for people on short breaks are centred on those completed indoors and in groups. People have an expectation and a right to meaningful activity which is an integral part of their care and not an ‘optional extra’\(^50\). All service users are to be given a role in selecting and planning activities where appropriate, and are supported to take part in activities outside of their normal care environment to encourage activity and engagement in the local community.

All short break services will be supported by an activities coordinator who has specific knowledge and training on activities for people with dementia. Short break services and the activities employed within them will focus on reabling and developing service users wherever possible, and maintaining skills and functionality.

\(\text{We don’t plan anything, we discuss things and we have ideas. As for us putting it in a diary... that might not work...it depends on staff, it depends on transport, it depends on the clients ourselves because we change our minds... we all compromise... we can do things this way because of the small group. (Service user with dementia)}\)

\(\text{Well, sometimes you come in [to respite] and you sit and look at one another... I need something more, I need to be occupied, I’ve always been wanting to be occupied and even though I am sitting in this [wheelchair] I still feel I can do it. (Service User)}\)

\(^{48}\) SIGN 86 (2006).

\(^{49}\) Care Commission & Mental Welfare Commission for Scotland (2009). Remember, I’m Still Me

\(^{50}\) Ibid
4.9.2 Care plans used during short breaks are developed in partnership with the person with dementia, their carers, family and coordinated with other care providers in order to ensure seamless provision of care which meets the individual need.

As highlighted in Sections 4.7.2 and 4.10.4 it is important to not only know about how a person lived before they developed dementia, but also to provide care in a continuous and coordinated manner. Care plans for people using a single service or a range are vital to the care they receive as they highlight the needs and preferences of the individual, important life history and will help care workers to individualise care and support the service user to maintain their identity. Information about the individual, their needs and preferences should be added to care plans whenever it comes to light, not only during period of formal review, and should be communicated across service providers. This will help to ensure the care plan is person centred and comprehensive and that all staff have access to the knowledge and information which allows them to provide high quality individualised care.

4.9.3 Improve processes for information sharing between service providers and service users and their carers, including information on day to day activities. This should include a method for service users and carers to feed into services to assist in their development.

Research shows participating in short break services can have positive impacts for both the person with dementia and the carer, and that the benefits are greatest when short breaks are regularly attended. However, it has also been shown that many carers are not utilising short break services due to “beliefs that it would cause more stress than relief, and difficulty in gaining consent from care recipients”. In order to achieve successful respite, the caregiver requires a full understanding of the service provided, and how it benefits them and the cared-for. This process can be assisted by the provision of information, emotional support and training during the respite period.

In addition to information provision and support, caregivers viewed their involvement in the respite care process as unsatisfactory, and that the nature of the relationship between the carer and care-staff was a significant factor in

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54 Ibid.
determining the quality of carer involvement in the service. A more inclusive and involved approach to short break provision for the carer and person with dementia may thus not only improve the quality of care received, it may also lead to increased satisfaction, increased use and ultimately greater benefits.

In order to ensure the person with dementia, their carers and family are all involved in the development and provision of care, a gradual and supported introduction scheme will be developed whereby the service user and their carer are invited to visit the place of stay, have an opportunity to meet care staff and become involved in daily activities prior to staying for a full day or overnight. A similar service will be available in the home where this is the location of the short break, and also in care homes (see section 4.10.1). This will help to build service user confidence in the service and ease transition, ensure service users have a full understanding of the service, how it benefits them, and how the carer and person with dementia can be involved in the planning process. The scheme will focus on learning from and sharing information with the person with dementia, family and carers as they transition into attending regular short breaks, and will ensure services are centred on the individual’s needs and history.

Managers of short breaks within the Council and NHS will work together to develop a standardised method for carers and people with dementia to provide ongoing information, ideas and feedback to short break services. The method must take into account the abilities of each service user and be able to adapt to suit their needs and service providers skilled in discussing and responding to the information presented.

Respite is quite difficult to get into…once for instance I was due to come in at a certain time and it was cancelled at the last minute and I was sent to another place which I wasn’t very happy about you know. (Service User)

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4.10 Long Term Care Facilities

AIM

People living with dementia in long term care receive quality care which meets their needs. Care is provided by well trained staff, in an appropriate environment and with meaningful activities. Each facility will be supported by a specialist mental health liaison service, and will work to improve communication between residents’ families and make greater efforts to integrate into the local communities. Council owned care homes will act as centres for care, where information is shared amongst care at home, short break and long term care services that provide a complete spectrum of care in and for the community.

RECOMMENDATIONS TO ACHIEVE THIS

4.10.1 Staff at all levels are educated and supported to provide individualised care, and designated dementia care facilitators are identified within each facility.

In Fife services continue to be developed to meet the needs of an increasing number of people living with dementia in the community, however it is recognised that for some people with dementia living in a long term care facility may be the most appropriate and effective way of meeting their individual needs. There are a number of facilities within Fife that provide a high standard of care for people with dementia; however, as highlighted by the recent report Remember, I’m Still Me\(^{56}\), this is a minority.

Currently there is an estimated 5700 people with dementia living in Fife. Approximately 63.5% of these people live in their own home in the community, while the remaining 36.5% live in long term care\(^{57}\). An estimated 700 people living in long term care with dementia have not received a medical diagnosis of dementia\(^{58}\). Consultations in Fife have shown that long term care staff recognise that a number of people have undiagnosed dementia, but they feel that there is 'no real point' in getting a diagnosis. This is not true as there are benefits in diagnosing progressed cases of dementia including increased understanding of the person and potentially their behaviour, reduction in

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**Long Term Care Facilities** - A term used to refer to an array of residential facilities which provide long term care. These commonly include care homes (residential and nursing) as well as long stay and continuing care wards in hospital. Other, non-residential services which provide long term care are addressed in Care at Home (4.7) and Short Breaks (4.9).

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\(^{57}\) Alzheimer’s Society (2007). Dementia UK.

incorrect prescribing, and more suitable social and activity opportunities. It is not clear whether the majority of people with undiagnosed dementia in long term care have developed dementia while in care, or if it was present prior to admission; however it is clear that care staff, if properly educated, may play an important part in facilitating a diagnosis.

In order to ensure people with dementia are receiving the care and support they deserve, staff at all levels in long term care facilities throughout Fife must be educated and supported to provide individualised care. This will be achieved through joint working across all care home providers in Fife to develop a comprehensive training programme which is easily accessible, can be completed during down times or can be accessed at home, and allows staff to explore and improve their attitudes and knowledge of dementia.

Each long term facility in Fife will also appoint a dementia care facilitator who will assist in the development, care and review of people with dementia. The dementia care facilitators will be well trained on providing care for people with dementia, and will form a network throughout Fife to facilitate the transfer of knowledge and good practice through informal and formal discussions with staff and by working with service users.

In addition to development opportunities surrounding the provision of care and support to people with dementia living in long term care, the Fife Telecare Development Programme will work with care providers to educate them on the role telecare and assistive technologies may play in care facilities. Many telecare technologies are of equal value in care homes as in people’s own homes. For example door exit monitoring systems and motion detectors may help to reduce the risks of nocturnal walking, falls detection and prevention systems and GPS tracking for safer walking may all be used to improve the independence and quality of life of people living with dementia in a care home.

4.10.2 Staff and residents in all long term care facilities will be supported through a specialist mental health liaison service.

Staff working in long term care facilities throughout Fife have a challenging role in providing a vital service to a wide range of people with unique physical and mental health conditions and needs. In order to provide a high quality service they must be supported by management and through investment in developing their skills and knowledge, and have ongoing support from and access to specialists with comprehensive knowledge on key conditions or issues. Support from specialist services may help prevent admissions to hospital or transfer to another home, reduce the use of inappropriate medications and may promote better care practice and boost staff confidence and morale.

One model which has been successful at reducing unnecessary admission into hospital, and is highly regarded by social and health care providers alike is the Care Home Specialist Mental Health Liaison Service (See good practice box). The Liaison Services, which have existed in various forms throughout
Fife and could cover all long term care facilities, share similar objectives which include:

- To build up lines of communication between care facilities and mental health services;
- To prevent unnecessary admissions of people with dementia to hospital;
- To assess long term care residents that are presenting with challenging behaviour in the home;
- To provide advice, guidance, and areas for further education on caring for people with dementia in long term care;
- To develop the skills of care workers in recognising, taking appropriate actions to lead to a diagnosis if necessary, and caring for people with mental health conditions;
- To liaise with medical staff (including GPs) for advice on residents;
- To involve additional services (occupational therapy, physiotherapy & psychology) where appropriate; and
- To evaluate the effectiveness of the advice and review care.

In order to improve the quality of care older people with dementia receive in long term care, and the support available to staff, it is recommended that a comprehensive business case highlighting the financial and non-financial benefits of the Liaison Nurse Service will be prepared and taken to the Health and Social Care Partnership Group with recommendations for the introduction of Specialist Mental Health Liaison Nurses to support long term care facilities across Fife. In addition to the roles highlighted previously, it is also expected that the Liaison Nurse will: 1) assist in identifying patients with an undiagnosed cognitive impairment and facilitating a diagnosis, and 2) work with care workers in an effort to reduce the unnecessary use of psychotropic medications in people with dementia.

### Care Home Specialist Mental Health Liaison Service

In 2005 a need was identified to reduce the number of inappropriate admissions for inpatient assessments of people with dementia from care homes. The service was initially developed with six senior staff nurses serving six care homes within existing resources in the North East of Fife. The service was very well received with an overwhelming positive response and in 2007 a pilot scheme was expanded to cover 19 homes in the North East. Key findings from an evaluation conducted in 2007 showed that the service was used regularly by over 75% of participants who found it very helpful. Every participating facility wished the service to continue, and GPs in the area felt the service filled a vital gap between Health and Social Care Service.

4.10.3 Improve the involvement and integration of carers, family, friends and the community into long term care facilities.

The choice to move into a long term care is never one taken lightly by anyone involved, and can be very distressing for both the carer and the person with
dementia. Prior to admission into care a number of important events should occur to prepare the person with dementia, their family, and the care facility which they will be entering for their arrival. Special attention must be given to the person with dementia and their carer as needs are assessed and a care plan is developed. Currently the carer is generally left to cope alone with very little or no psychological support, and the same is true for the person with dementia. This is despite studies which have shown that the psychological burden continues once the person with dementia has been admitted into long term care\textsuperscript{59}, and that increasing stress and burden experienced by carers of people with dementia is linked with worsening depression in both groups\textsuperscript{60}.

A study published in 2005\textsuperscript{61} showed that approximately a quarter of carers of people with dementia in care homes felt that care facilities could do more to help them become/remain involved in care. Areas for improvement included: more frequent communication from the place of care; greater involvement in activities; advice regarding how they can become more involved; and staff being more responsive and open about problems at the facility. In order to better provide a service for carers of people with dementia, long term care facilities must ensure that carers are also provided a person centred approach. The outcomes of this approach will be unique for each individual, and may mean, for example, increased involvement in the development of the person’s care plan, a gradual introduction into care, and opportunities for counselling and support services during transition periods.

In order to improve the involvement and support of carers, families and friends of people living in long term care, a gradual and supported introduction scheme will be developed and utilised wherever possible and appropriate. The scheme will involve their carer, family and friends to ensure that the care plan is suited to the individual needs and life history of the person, and will promote the continued involvement of personal networks and supports. The gradual introduction scheme will be part of a programme developed by long term care facilities aimed at involving and supporting carers and people with dementia, and utilising their expertise.

Long term care facilities will also work to improve their integration into the community by both inviting the community in and also engaging in activities and events out with the home. Being active members of the local community will not only reduce the stigma that is commonly held about care homes, but may also improve the quality of life of the residents who will have increase social and occupational opportunity.


4.10.4 Care plans are developed in partnership with the person with dementia, their carers and family and are individualised to each resident in order to provide the right care to meet their needs.

As highlighted by the recent report *Remember, I’m Still Me* and in Sections 4.7.2 and 4.9.2 it is important to know about how a person lived before they developed dementia. Care plans for people living in long term care are vital to the care they receive as they highlight the needs and preferences of the individual. Recording personal information and a life history will help care workers to individualise the care of the person with dementia and support them to maintain their identity. Information about the individual, their needs and preferences should be added to care plans whenever it comes to light, not only during periods of formal review. All staff should have access to and regularly review the knowledge and information stored in a care plan which will allow them to provide appropriate individualised care.

In line with the National Care Standards for Care Homes, all care homes will work with people with dementia to develop comprehensive care plans which include life histories and a personal plan which details the needs and preferences of the person with dementia and sets out how they will be met. It is recommended that these principles are extended across all long term care facilities in Fife including care homes and long term care wards.

In order to achieve this Fife Council Residential Care Services will work in partnership with NHS Fife staff and independent providers to redesign the current care plan template, ensuring there is adequate space and direction to include personal and individual details. These will be based on similar care plans which have been successfully used in learning disability and children’s and family services. The universality of care plans used in Fife will be welcomed by emergency services and carers alike as it may improve ease in access and understanding. All care workers in long term facilities will receive training on developing care plans including the addition of information collected during both informal and formal reviews.

> My husband has been here (in care) for some years. He came here initially for day care, regularly, and then he came into respite to give me a break. And then, eventually, I was getting as old as he was and so he came here. I cannot remember how long he has been…but he came here so regularly, it was like his second home. He called it his condo. (Carer)

4.10.5 Ensure all long term care facilities have regular involvement of trained activities coordinator who works with the care staff to provide meaningful activities to residents on a regular and ongoing basis.

As highlighted in Section 4.9.1 activities and programmes must be available which are suited to the individual and based on an understanding of what gives their life meaning. Activities for people in long term care must be a

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regular part of their daily care, and should be individualised to satisfy their needs and preferences. Activities that centre on the person’s normal daily life and events, such as preparing a meal, and visiting a local shop or familiar sight, improves the service user’s quality of life and can positively affect mortality, depression, physical function and behavioural symptoms for people with dementia, and improve self esteem and sense of identity.

People living in long term care have an expectation and a right to plan and participate in meaningful activity as an integral part of their care and not an optional extra. All service users are to be encouraged to assist in selecting, planning, and taking part in activities where appropriate. Activities should be available within and outside the place of care as a regular part of daily living – allocated activity time must not be the only time activities are engaged in and all staff must contribute to the daily activities of residents.

In order to ensure meaningful activities are provided for all residents, including those with dementia, all long term care facilities will have access to a trained activities coordinator who will have dementia specific activities knowledge and will work with care staff to assist them in providing opportunities to participate in individual and group activities on a daily basis to residents. Fife Council activities coordinators will work with other providers to ensure staff are trained and supported to provide meaningful activities to all residents.

In addition, and in line with the recommendations made in the recent report on care homes and the National Care Standards which indicate people living in care homes should “be supported and encouraged to use local services such as hairdressers, shops and banks”, all people living in long term care will be given more opportunity to participate in activities outside of the place of residence. It is recommended that people living in care facilities have a minimum of two opportunities per month to participate in activities away from the facility which are suited to their abilities and tastes. This should be increased over time.

In addition to activities outside of the care facility, there is also a need to increase access to and utilisation of gardens and outdoor areas. During consultations for the Strategy many service users reported a desire to use outdoor spaces more, but experienced difficulty in doing so due to physical restrictions or a lack of staff availability to assist them. Garden and outdoor spaces offer valuable opportunities for occupation, mental stimulation, as well as offer physical and psychological benefits. Appropriate plans to increase outdoor activities and use opportunities to use the garden must be made by care staff.

64 Care Commission & Mental Welfare Commission for Scotland (2009).
65 Ibid.
66 National Care Standards for Scotland: Care Homes for Older People.
4.10.6 Establish new and strengthen existing communication networks and standard methods for information sharing across the range of community and long term care services to encourage knowledge transfer.

As highlighted in Section 3, there is a great deal of dementia specific knowledge and expertise within Fife and within long term care staff. However, at present this knowledge is not being effectively shared and disseminated, thus limiting the number of service users who benefit from it. In order to improve the quality of care, providers must work together to share ideas and experiences, learning from one another about what has worked and what hasn’t.

Fife Council care homes currently share best practice ideas and experiences through the Good Practice with Dementia Group. The Group meets bi-monthly and focuses on learning from experiences and innovative practices in their partner care homes. To date sessions have included life-story work, doll-therapy with people with dementia, recognising and managing pain in dementia, and the use of new communication techniques such as Talking Mats©. In order to facilitate knowledge transfer and joint working across all long term care facilities in Fife, the Group will hold quarterly discussion forums focused on disseminating best practice for people with dementia and opened to facilities throughout Fife.

Researcher: Is there anything that you used to do at home that you don’t get to do here (in the care home)?
Service user 2: I would like to go out more. To the park, or for a drive, a run, you know?

Service user 1: At the end of the month we are going to Kinross.
Researcher: Right. And how often do you normally get out [for activities]?
Service User 1: Oh, about every three months or something like that.
4.11 Hospital & Acute Care

AIM

People with dementia who have medical needs requiring hospital care are cared for in a suitable environment by well trained staff that are skilled in working with people with complex needs such as those of someone with dementia. Support will be available from a multidisciplinary Old Age Psychiatry Liaison Service, and all patients are given an appropriate assessment which leads to a care pathway suited to their needs.

RECOMMENDATIONS TO ACHIEVE THIS

4.11.1 Hospitals and clinical staff work to implement changes to the environment and care practices which have been shown to improve the experience of people with confusion in the hospital.

While in Accident & Emergency and acute care people with dementia are exposed to an increased number of stimuli and an unfamiliar environment, often all at once. These environments are busy and noisy with the constant sounds of people talking, telephones ringing, alarms going off, doors opening, and various individuals asking questions and performing care tasks. For patients with dementia the exposure to these stimuli and the change in routine can result in the patient experiencing significant distress. This distress may be communicated through behaviours that are seen as disruptive or challenging for care staff.

As highlighted in recent guidance issued by the Scottish Government\(^67\), a number of practices can improve the experience of people with dementia in the hospital including: ensuring all older people with apparent confusion are given an appropriate psychological and physical assessment, ensuring each person is introduced upon each entry, providing simple explanations of what they are doing and why, minimising the number of staff carrying out a procedure, minimising the number of bed moves made, and appointing a key staff member to work with the individual with dementia whenever possible.

Staff are often faced with additional tasks when caring for someone with dementia as not only must they respond to the person’s physical care needs, but must also become involved in the management of the individuals psychological needs including behaviours such as walking and vocalisation. These behaviours impact on the nurses, the outcomes for the person with dementia, and they also frequently impact on the care and outcomes of others within the hospital environment\(^68\). All staff working and interacting with patients in the hospital will receive dementia awareness training, with those


responsible for providing care receiving more in depth training. As highlighted in Section 3, work will be done with academic and professional institutions to promote the inclusion of dementia training in the further education training of all relevant professions.

It is largely accepted that the current acute care environment is not ideal for serving the aging population and experts believe that hospitals must begin to adapt to the changing needs of society. In order to achieve best practice in designing an acute environment for people with dementia large scale investment in new and existing buildings is required. In the current context in Fife this is not feasible, however with new developments to the acute hospitals in Fife planned and some underway, the use of dementia friendly design principles should be implemented. As the Victoria Hospital is being redesigned largely in recognition of the changing demographic which has led to changing needs and demands, it is most appropriate that the needs of people with dementia are met.

Without physically altering buildings there are a number of small changes that can be made to the environment and to the caring practices which will assist in improving the experience of people with dementia. Some of these include maintaining a calm environment which is well organised, free of clutter, and familiar will assist people who are confused.

NHS Fife Dementia Awareness Training

NHS Fife currently offers Dementia Awareness Initially this was targeted at mental health nursing assistants; however it has now been rolled out to all grades of staff within Mental Health Services. The training is delivered through the Clinical Governance Department and focuses on the principles of providing person centred care to people with dementia, care planning and communication. The training has been underway for one year and approximately 150 individuals have completed it. An evaluation was complete in June 2008 when a wide variety of nursing and non-nursing staff were invited to attend and evaluate the programme. The response was overwhelmingly positive and continues to be so, with a number of requests for more widespread roll out across NHS staff.

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4.11.2 All people over the age of 65 receive a comprehensive geriatric assessment during admission to hospital.

In 2008 in Fife 55% of acute medical admissions were patients over the age of 65 years. An estimated 33% of these admissions had a significant cognitive impairment. A number of these patients may not have had an acute medical condition but were being admitted due to a lack of an alternative service to meet their needs. Despite this, it remains the case that in the acute environment the focus of assessment and care is on the patients’ physical condition, and their dementia or other mental health conditions are often overlooked. When hospital staff fail to identify or deal with the whole person, including their dementia, it can lead to longer stays and poorer outcomes than for people who are psychiatrically well.

A recent review of the use of the admission assessments used in Fife highlighted a lack of coordination in elderly patients admitted to acute medicine which resulted in problems further along the patient’s journey as their needs were insufficiently documented and addressed. Since recognising and assessing an individual with a potential cognitive impairment is the first step to providing person centred care in any environment, a more holistic approach better suited to the older person is necessary. In some cases it may be the first step towards receiving a diagnosis and getting the appropriate treatment and intervention.

The comprehensive geriatric assessment assesses an elderly person’s physical, cognitive and mental health, as well as the functional ability and socio-environmental situation of the individual. The introduction of such a holistic assessment is thought to have a significant benefit to people with mental health conditions such as dementia in the hospital setting and is currently being piloted in Fife. The assessment framework will be evaluated, and if positive will be rolled out to all appropriate settings in Fife.

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Medical Admissions Unit Comprehensive Geriatric Assessment and Triage

The Medical Admissions Unit in the Victoria Hospital Kirkcaldy is involved in a pilot project to develop the use of a comprehensive geriatric assessment and triage programme. All patients over 65 and admitted to the unit will receive an assessment within 24 hours of admission. The main domains of the assessment surround physical health, functional ability, cognitive and mental health and factors that affect the person’s socioeconomic situation. Using this tool will allow for a more reliable and efficient evaluation, and improved communication between health care providers. All of these aspects can positively impact the care of someone with dementia in the hospital.

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4.11.3 All acute and community based hospitals work with a specialist Older Age Psychiatry Liaison Service.

In the current hospital setting people with dementia or cognitive impairment may be admitted to a number of different wards depending on their acute medical needs. Amongst care staff and wards there is marked variation and deficit in knowledge and skills in caring for people with dementia. This will be addressed by improved training; however specialist support will be required.

The NHS Fife Mental Health Service provides an Old Age Psychiatry Liaison Service which covers Victoria Hospital in Kirkcaldy. This service comprises a specialist Mental Health Liaison Nurse (working office hours only) supported by dedicated time from an Old Age Consultant Psychiatrist. The primary role of this service is to improve the care of older people with mental health problems in the hospital (see Good Practice Box below).

Liaison services of similar models have recently been advocated by the National Institute for Clinical Excellence due to their ability to provide rapid and high-quality specialist assessments as well as input into care planning.

In order to ensure all people with dementia in Fife are receiving care from well trained and knowledgeable staff while in hospital, the Liaison Psychiatry Service should be expanded to include comprehensive coverage throughout both acute and community hospitals across Fife. Such a liaison service should ideally comprise a multidisciplinary team following guidelines provided by the Royal College of Psychiatrists.

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**Old Age Psychiatry Liaison Service**

The primary objective of the Mental Health Liaison Nurse (MHLN) is to improve the care of older people with mental disorders in the Victoria Hospital. The nurse is supported by an Old Age Consultant Psychiatrist with time dedicated to the service. The liaison model is proactive, focusing on collaborative working to provide a timely response to referrals and ongoing frequent review if necessary. The MHLN assesses new referrals and, with the assistance of the Consultant Psychiatrist, provides advice and support on a range of issues including diagnosis, medication and potential discharge options. There is a clear referral protocol and operational policy outlining service objectives. The service also offers training and educational programmes on mental health issues. The most common reason for referral is problems related to confusion and dementia.

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71 House of Commons - Public Accounts Committee (2008). *Improving Services and Support for People with Dementia*.
74 Who Cares Wins - Improving the outcome for older people admitted to the general hospital: Guidelines for the development of liaison mental health services for older people (2005). Report of a working group for the Faculty of Old Age Psychiatry, Royal College of Psychiatry.
4.12 Emergency Services

AIM

Emergency service providers are equipped with the skills and knowledge to effectively work with people with confusion or memory loss. Effective communication skills and being able to recognise when somebody may have dementia is an important part of many services provided by the Fire, Police or Ambulance Service, whether it is as a preventative measure or during a period of acute need.

RECOMMENDATION TO ACHIEVE THIS

4.12.1 Fife Council and NHS Fife work jointly with Fife Constabulary, the Scottish Ambulance Service and Fife Fire & Rescue to develop an appropriate level of dementia awareness.

Fife Constabulary, Fife Fire and Rescue Service and the Fife branch of the Scottish Ambulance Service all play an important role in the lives of older people and people with dementia. All three services work on a regular basis in community outreach work to improve the lives and reduce the risks of older people, and also in emergency situations as required.

Fife Fire and Rescue Service has identified older people as one of the at risk groups for having a fire in their home, and thus do preventative education and fire safety visits throughout Fife. The Scottish Ambulance Service works with older people daily through their patient transport service, and the Police play a key role in ensuring community safety and protecting vulnerable people such as those with dementia. They may be involved with a person with dementia in a number of routine and emergency situations which require that the worker involved is able to identify and respond to the needs of the individual.

In the short term this can be achieved by each service working jointly with NHS Fife and Fife Council to develop or participate in local dementia training and awareness events. In the long term it is necessary that staff are appropriately trained during induction with additional opportunities for ongoing development available. For all three organisations induction training in completed at a national level and thus work must begin here.

Additionally, ensuring emergency services have access to the right information is often essential to the success of any operation. As highlighted throughout this document, appropriately crafted care plans may play an important role if someone with dementia is missing or requires emergency care. It is thus essential that care plans are kept up to date, have an appropriate amount of information and that emergency services are aware of how to rapidly access them.

Also, Fife Telecare Development programme will continue to extend its work with emergency services. Currently the Telecare Programme Team is working
with Fife Fire and Rescue Service and Fife Constabulary who have an interest in the development of telecare to assist them to support people with dementia in the community. Fife Fire and Rescue Service personnel providing home fire safety checks can refer appropriate service users to the Social Work Service and the Telecare Team for smoke and gas detectors. And Fife Constabulary is a partner in the Telecare Development Programme’s 2009/10 pilot of the Global Positioning System which is being used to improve the safety of people with dementia who like to walk and travel alone and are at a high risk for becoming disorientated or lost.
4.13 Palliative & End of Life Care

AIM

People with dementia and their families receive care that integrates a palliative approach and is of high quality through to the end of life. The care delivered is based on planning by the person with dementia and their family which is completed following diagnosis and reviewed regularly.

RECOMMENDATION TO ACHIEVE THIS

4.13.1 Ensure the needs of people with dementia and their carers are recognised in the development and delivery of the Living & Dying Well Local Action Plan.

Many people traditionally associate palliative care as an approach which is employed as a person nears the end of life; however the palliative care approach extends far beyond this. It focuses on the person, not the disease, and applies a holistic approach to meeting the physical, practical, functional, social, emotional and spiritual needs of patients and carers facing progressive illness and bereavement. In order to improve the care of people with dementia it must be recognised by everyone involved in their care recognises this.

Dementia is not often viewed as a terminal disease, likely due to its progressive nature. However, as highlighted in Living & Dying Well, palliative and end of life care are integral aspects of the care delivered by any health and social care professional to those living with and dying from any advanced, progressive or incurable condition\(^75\). Unlike cancer, organ failure or other terminal conditions, it can be very difficult to accurately assess when a person with dementia reaches the terminal state (less than 6 months until death), and for this reason end of life care plans are not considered or prepared by the majority of people with dementia until they have significantly progressed, often beyond the point of having sufficient mental capacity to make decisions.


*Having Alzheimer’s, you’re alright today, you might not be alright tomorrow, sort of thing. You might not be alright next week, next month, next year. You might be alright for another 20-30 years. You don’t know. So therefore you put that (plan) into place.* (Service user with dementia)

*[At the end of life] you want somebody who cares, and they need to know what to do with you…I made sure my sister and daughter know what I want. And they say to me, they say to me “oh, do not talk about it”. But I say “No. I’m wanting to speak about it before anything happens to me.” They know what to do.* (Service user)
consistent with the principles laid out in legislation\textsuperscript{76} such as the Adults with Incapacity (Scotland) Act\textsuperscript{77}.

As dementia progresses the person loses cognitive function which may make it difficult for them to communicate their views and wishes. This, in turn, often results in formal care staff turning to the carer for assistance in decision making which may increase the emotional burden on the carer. End of life planning must take place early by an individual trained in communication and counselling and while the person with dementia has sufficient mental capacity. This could include advance care statements or lasting power of attorneys. IN developing such plans service users should be offered support from advocacy organisations. Providers of care must be aware of such plans, ensure they are recorded and communicated to care staff and appropriately utilised.

A palliative care approach should be used as appropriate alongside the active management of dementia using person centred care following the diagnosis. The Gold Standard Framework for palliative care of people with dementia and the Liverpool Care Pathway are important parts of the dementia specific Integrated Care Pathway and will be implemented as a part of the Local Action Plan for Living & Dying Well which is a comprehensive plan aimed at improving palliative and end of life care for people in Fife living in a variety of settings including their own homes, care homes and in hospital. It focuses on improving joint working to ensure that timely, holistic and effective care planning is available for those with palliative and end of life care needs and is carried out in a manner which is person centred and responsive to the needs of the person. The action plan aims to achieve this by improving staff education and training across all health and social care sectors, developing multi-disciplinary palliative care networks, and introducing standardised methods for assessing and delivering palliative and end of life care.

In order to ensure people with dementia are cared for using a palliative approach, dementia will be included in the implementation of the Living & Dying Well local action plan, and recognised as a progressive and incurable condition which benefits from a palliative approach. Staff working in the community will work in partnership with care home staff to undertake training on palliative and end of life care.

\textbf{Palliative Care Champions Delivering Training across Care Services}

Palliative Care Champions in Fife Council care homes have been trained by the NHS Fife Macmillan Cancer and Palliative Care Educator within to facilitate small groups of care workers through a training programme with the assistance of experiential discussions and learning, and work booklets. The programme, the Macmillan Foundations in Palliative Care, has four focal areas: principles of palliative care; bereavement; pain and symptom management; and communication.


\textsuperscript{77} Adults with Incapacity (Scotland) Act 2000.
SECTION 5
Implementation & Delivery

AIM

Ensure effective local leadership across Fife which will support the implementation of the Strategy. Support is required at all levels throughout NHS Fife and Fife Council to drive the implementation of the Dementia Strategy forward, and to ensure implementation leads to better integrated and higher quality services for people with dementia and their carers throughout Fife.

RECOMMENDATIONS TO ACHIEVE THIS

5.1 Using action plans to create change.

In addition to the Strategy a corresponding Implementation Plan will be designed consisting of comprehensive action plans which identify individuals and services to work together to lead each action.

Implementation support across Fife and at local levels is required to ensure the Strategy is implemented in a way which achieves its intended outcomes – better quality, more responsive and more accessible services in which there is equality in access for people affected by dementia throughout Fife.

5.2 Leadership for dementia care in Fife.

Fife has been the recipient of many strategies or documents promoting change in recent years, the most successful of which have had designated local leadership and management support. A number of reasons have been discussed and efforts made to resolve the barriers faced in improving dementia care, and it has become apparent that one of the challenges is a lack of a clear and agreed Strategy to guide developments and work across Fife. This Strategy, if supported by Senior Management and implemented effectively, has the potential to reduce the disparity in service quality and access across Fife which have formed over the years in a financially efficient manner.

In order to achieve the changes laid out in this document the appointment of a Lead to oversee the work is recommended (3.1). The Lead will work close with the Mental Health and Older Peoples Strategic Implementation Groups to ensure services and organisations are working together to change as efficiently and effectively as possible. They will be responsible for liaising with the local leads as agreed in the implementation plans, and for realising actions, as well as anticipating and responding to new challenges.

It is recommended that the Lead for Dementia in Fife be initially supported by short life Steering Group composed of key individuals from across Fife.
involved in providing care for people with dementia. This person will work with the Health and Social Care Partnership and lead the prioritisation and implementation of the Strategy.

5.3 Measuring for change.

The development and implementation of a virtual care management system for dementia (Section 4.1.3) will play an important role in measuring change and future planning. Key evaluation measures have been identified for many of the recommendations, linking into current measures used, and in rare cases requiring the development of new measures. The information collected can be used to develop a comprehensive picture of changes in dementia care in Fife as well as to plan future services.

The team responsible for developing the virtual care management system must work jointly across services and providers and with the Mental Health Collaborative who all have interests in gathering information on dementia diagnosis and care in an effort to improve services.

Each recommendation for improvement to dementia services in Fife has been broken down into a series of action points, each of which must have an identified measure which will be used to promote understanding of the impact of each change and monitor progress.

5.4 Annual reporting.

The Fife Mental Health and Older Peoples Strategic Implementation Groups will monitor the progress of the Strategy and contribute, in partnership with the Dementia Lead in Fife and the Strategy Steering Group, to an annual report to the Health and Social Care Partnership using agreed measures.

Respective leads identified and Dementia Lead for Fife.

5.5 Sharing practice to encourage change.

Structured methods for information sharing and knowledge transfer will be set up to ensure learning and best practice is effectively communicated. A number of groups and forums identified throughout the Strategy can be utilised in this manner. As well, new training programmes and tools will be developed in light of best practice in knowledge transfer and used for both service providers and users.

Progress reports on the implementation of the Strategy will be distributed across Fife through the Steering Groups.

5.6 Implementation Timeline

The timeline presented indicates the completion of major changes to services in Fife. It is intended as a visual summary as many of the changes highlighted
are the result of a series of smaller changes which will be identified in the Implementation Plan.

<table>
<thead>
<tr>
<th>Year</th>
<th>Initiative Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>Carers Strategy reviewed (4.4.1) &amp; improved use of Carers Assessments (4.4.2)</td>
</tr>
<tr>
<td>2010</td>
<td>Improved use of Telecare &amp; assistive technology by people with dementia (4.7.4)</td>
</tr>
<tr>
<td>2011</td>
<td>Lead for Dementia Services in Fife identified (3.1)</td>
</tr>
<tr>
<td>2012</td>
<td>Appropriate clinical capacity to identify dementia and lead to a diagnosis (4.1.1)</td>
</tr>
<tr>
<td>2013</td>
<td>Improved dementia skill and knowledge among health and social care providers (3.3)</td>
</tr>
<tr>
<td>2014</td>
<td>Home care reablement and specialist dementia home carers identified (4.7.1)</td>
</tr>
<tr>
<td>2015</td>
<td>People with dementia receive appropriate treatments and reviews (4.2.1)</td>
</tr>
<tr>
<td>2016</td>
<td>Improved access to dementia resources for professionals and public (3.4)</td>
</tr>
<tr>
<td>2017</td>
<td>General and targeted awareness campaigns complete (3.2)</td>
</tr>
<tr>
<td>2018</td>
<td>Single shared care plans used across health and social care services (4.7.2)</td>
</tr>
<tr>
<td>2019</td>
<td>Dementia Advisor position reviewed and implemented as appropriate (4.3.1)</td>
</tr>
<tr>
<td>2020</td>
<td>People with dementia have improved access to appropriate transport options (4.7.5)</td>
</tr>
<tr>
<td>2021</td>
<td>Comprehensive geriatric assessment used in admission units in hospitals Fife-wide (4.11.1)</td>
</tr>
<tr>
<td>2022</td>
<td>Housing needs of people with dementia identified and options improved (4.5.1)</td>
</tr>
<tr>
<td>2023</td>
<td>Improved care (4.10.1), activities (4.10.3) and user involvement (4.10.2) in all care homes.</td>
</tr>
<tr>
<td>2024</td>
<td>Improved Intermediate Care options available for people with dementia (4.6.1 &amp; 2)</td>
</tr>
<tr>
<td>2025</td>
<td>Improved integration and working across all home care providers in Fife (4.7.3)</td>
</tr>
<tr>
<td>2026</td>
<td>Mental Health Liaison Nurses in Care Homes Fife-wide (4.10.2)</td>
</tr>
<tr>
<td>2027</td>
<td>Enhanced options for short breaks available for people with dementia in a variety of settings and in the evenings and weekends (4.9.1)</td>
</tr>
<tr>
<td>2028</td>
<td>Virtual joined up dementia care management system developed and utilised by health and social care providers is accessible Fife-wide (4.1.3)</td>
</tr>
<tr>
<td>2029</td>
<td>All new buildings in Fife are assessed against dementia design principles (4.5.2)</td>
</tr>
</tbody>
</table>
GLOSSARY OF TERMS

**Challenging behaviour** – Behaviour that is upsetting to the individual and/or could be dangerous to themselves or others.

**Dementia** – Dementia is a general term used to describe the loss of brain function including memory and the increasing lack of ability to carry out the full range of day to day activities. Dementia can also cause changes in personality and social behaviour.

**Dementia friendly** – A term used to describe an environment that has been adapted to suit the needs of people with dementia and enable them to make sense of their surroundings. For example, bedroom doors are personalised to assist people to find their own room easily.

**Extra Care Housing** – Accessible housing built and designed to facilitate the delivery of flexible, person centred housing support and personal care, available as required on a 24 hour basis. Accommodation is normally clustered but may operate on a hub and spoke or dispersed basis.

**Intermediate Care** – Services have been defined as those whose main aim is to prevent unnecessary admission or support discharge from hospital back into the community.

**Non-specialist Physicians** - Refers to physicians who do not have specialist training in working with older people or people with dementia. For example, this would include General Practitioners, Orthopaedists, Gastroenterologists etcetera.

**Palliative Care** - an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.  

**People affected by dementia** – This term is holistic and refers to people who have dementia, as well as their carers, family, friends, and community networks who will all be impacted by their condition.

**Person centred care** – There are a variety of definitions and understandings of the term ‘person centred care’. For the purpose of this Strategy person centred care refers to care which encompasses the following four principles:

- valuing people with dementia and those who care for them
- treating people as individuals
- looking at the world from the perspective of the person with dementia

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• a positive social environment to enable the person with dementia to experience relative well-being.

**Reablement** – The term reablement refers to models of care which support the active process of regaining skills, confidence and independence. They are generally services which have short-term intensive in-put.

**Sheltered Housing** – Accessible housing which is usually clustered, but may be dispersed and which benefits from a warden service and a community alarm service. The warden service provides housing support but not personal care. Personal care, if required, would be provided on an individual basis following assessment. No overnight cover or meals are provided.

**Very Sheltered Housing** – Accessible housing which offers all of the above and a full or partial meals service. Admission is usually on the basis of an assessment of needs and the warden service may offer more support than in sheltered housing. Overnight sleep-in cover may be available.
### APPENDIX 1: Prevalence of dementia in Fife

<table>
<thead>
<tr>
<th>Age range</th>
<th>Male Prevalence Rate</th>
<th>Female Prevalence Rate</th>
<th># Males with Dementia in Fife</th>
<th># Females with dementia in Fife</th>
<th>Total both sexes</th>
</tr>
</thead>
<tbody>
<tr>
<td>30-59*</td>
<td>0.16*</td>
<td>0.09*</td>
<td>114</td>
<td>68</td>
<td>182</td>
</tr>
<tr>
<td>60-64</td>
<td>0.2</td>
<td>0.9</td>
<td>23</td>
<td>111</td>
<td>134</td>
</tr>
<tr>
<td>65-69</td>
<td>1.8</td>
<td>1.4</td>
<td>155</td>
<td>133</td>
<td>288</td>
</tr>
<tr>
<td>70-74</td>
<td>3.2</td>
<td>3.8</td>
<td>225</td>
<td>316</td>
<td>541</td>
</tr>
<tr>
<td>75-79</td>
<td>7.0</td>
<td>7.6</td>
<td>357</td>
<td>520</td>
<td>877</td>
</tr>
<tr>
<td>80-84</td>
<td>14.5</td>
<td>16.4</td>
<td>491</td>
<td>884</td>
<td>1375</td>
</tr>
<tr>
<td>85-89</td>
<td>20.9</td>
<td>28.5</td>
<td>333</td>
<td>1001</td>
<td>1334</td>
</tr>
<tr>
<td>90+</td>
<td>29.2</td>
<td>44.4</td>
<td>164</td>
<td>855</td>
<td>1018</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>1860</strong></td>
<td></td>
<td><strong>3888</strong></td>
<td><strong>5748</strong></td>
<td></td>
</tr>
</tbody>
</table>

* Using General Register Office for Scotland 2008 demographic data and EuroCoDe prevalence rates

* Calculated using EuroDem prevalence rates for this age group

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APPENDIX 2: Projected prevalence of dementia in Fife 2008 – 2030

<table>
<thead>
<tr>
<th></th>
<th>2008</th>
<th>2015</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males with Dementia</td>
<td>1860</td>
<td>2369</td>
<td>2834</td>
<td>3391</td>
<td>3969</td>
</tr>
<tr>
<td>Females with dementia</td>
<td>3888</td>
<td>4524</td>
<td>5143</td>
<td>5980</td>
<td>6990</td>
</tr>
<tr>
<td>Total</td>
<td>5748</td>
<td>6894</td>
<td>7977</td>
<td>9372</td>
<td>10959</td>
</tr>
</tbody>
</table>

^ Using General Register Office for Scotland 2006 based demographic predictions data and EuroCoDe prevalence rates\(^2\)

\(^2\) Reynish E (2009).
# APPENDIX 3: Fife Dementia Strategy Working Group Membership

<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andrew McKay</td>
<td>Fife Council</td>
<td>Social Worker</td>
</tr>
<tr>
<td>Angela Dixon</td>
<td>NHS Fife</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>Barbara Mitchell</td>
<td>Fife Council</td>
<td>Social Worker – Enhanced Assessment &amp; Support Team</td>
</tr>
<tr>
<td>Brittany Ellis</td>
<td>Fife Council/NHS Fife/DSDC</td>
<td>Project Lead – Dementia Strategy</td>
</tr>
<tr>
<td>Craig Fenwick</td>
<td>NHS Fife</td>
<td>Old Age Consultant Psychiatrist</td>
</tr>
<tr>
<td>Emma Reynish</td>
<td>NHS Fife</td>
<td>Consultant Geriatrician</td>
</tr>
<tr>
<td>Fiona Kelly</td>
<td>DSDC</td>
<td>Dementia Lecturer</td>
</tr>
<tr>
<td>Frank Robinson</td>
<td>Fife Council</td>
<td>Team Leader – Adults Service</td>
</tr>
<tr>
<td>Gary Guichan</td>
<td>Fife Advocacy</td>
<td>Service Manager</td>
</tr>
<tr>
<td>Gary Stevenson</td>
<td>NHS Fife</td>
<td>Old Age Consultant Psychiatrist</td>
</tr>
<tr>
<td>Hilary Elsy</td>
<td>NHS Fife</td>
<td>Senior Clinical Effectiveness Practitioner</td>
</tr>
<tr>
<td>Julie Penn</td>
<td>Alzheimer Scotland</td>
<td>Fife Service Manager</td>
</tr>
<tr>
<td>Karen Robertson</td>
<td>Kingdom Homes</td>
<td>Representing Scottish Care Group</td>
</tr>
<tr>
<td>Ken Laurie</td>
<td>NHS Fife</td>
<td>Director of Strategic Change</td>
</tr>
<tr>
<td>Louise Bell</td>
<td>Fife Council</td>
<td>Service Manager – Older People</td>
</tr>
<tr>
<td>Louise McCabe</td>
<td>DSDC</td>
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APPENDIX 4: Dementia Advisor

The following is intended to act as guiding principles for the development of Dementia Advisors. Given the ongoing work in Fife and the UK on Dementia Advisors, as well as the changes that will result from the implementation of this Strategy, it will be necessary to review, and possible alter the focus of the posts prior to implementation in 2013.

The Dementia Advisors main role is to empower people with dementia and their family/carer to develop and utilise personal support networks and local services available in their area. They will do this through helping them to understand and cope with their diagnosis and prognosis, and providing information on local groups and services available to the person with dementia and their family/carer. They will also work with the local community, increasing awareness about dementia and developing services to become more inclusive of people with dementia and other mental health conditions.

Key tasks for the Dementia Advisor are indicated below and should be addressed by the Advisor as necessary/appropriate.

- Information on dementia, what to expect and how to plan including:
  - Dementia specific information/material;
  - Medication;
  - Coping strategies for person with dementia and family/carer;
  - End of life care planning/power of attorney
  - Welfare benefits;
  - Attendance allowance/disability living allowance;
  - Day to day activities;
  - Driving;
  - DVLA informed;
  - Carer support;
  - Occupational therapist input;
  - Employment;
  - Referrals to Social Work/Health; and
  - Maintaining social activities.

- Support and advice on sharing the diagnosis with friends and family.
- Improving dementia awareness in local services and groups.
- Empowering the person with dementia and their family in accessing local services and establishing local support networks.
- Work with primary care clinicians to promote understanding and awareness of dementia, the importance of receiving a timely diagnosis, and the benefits associated with early intervention.

Following intervention and based on the conversations shared, the Coordinator can refer the service user to additional services if appropriate.

The Dementia Advisor pilot will include a comprehensive evaluation which is developed at the beginning of the project, and which ensures data collection and effective learning.
The Dementia Advisor posts will each include part time administrative support (0.5 FTE).

In order to prevent variable service use from occurring with the introduction of the Dementia Advisor, all physicians involved in the diagnosis of dementia will be well-versed on the service and how it can be accessed. Part of the Coordinators post will be to meet with local health and social care providers in the area they cover, to inform them of their post and to identify ways they can work together and provide services for people with dementia most effectively. The scope of the post will be broad and flexible, allowing the post holder to work in the most effective way to improve dementia services.

As General Practitioners (GPs) are often the point of entry for a person with suspected dementia and are informed of every one of their patients who receives a diagnosis, the Coordinator will primarily work with them to promote awareness and understanding of dementia, and to ensure all individuals with a diagnosis are referred on to their service.

All people who are diagnosed with dementia will be offered a referral to the Dementia Advisor from their GP as the primary point of referral. Referrals will be made immediately following diagnosis. The Advisor will remain with the person with dementia and their carers throughout the duration of their illness. Support and contact will be individualised and more intense during the first 10-12 weeks following diagnosis and in agreement with the service users wishes, and will be gradually reduced. The support will remain available throughout the duration of their condition, and the carer and person with dementia can contact their Coordinator directly in the future.
APPENDIX 5: The Local and National Policy Context for the Fife Dementia Strategy

Local Context

Community Cares Framework - Single Outcome Agreement between Fife Partnership and the Scottish Government: Fife’s SOA identifies priorities and areas for improvement that will deliver better outcomes for the people of Fife. The SOA brings together the priorities of the Fife Community Plan and the contributions to the delivery of the outcomes by each of the Community Planning Partners. It focuses on the following four outcomes: educational achievement for all, tackling worklessness, conserving energy and resources, and keeping Fife connected.

Dementia Integrated Care Pathway: The Fife Dementia ICP focused on achieving agreed outcomes for individual users of the services. They are a means of recording any variations from best practice and identifying and addressing gaps in the care of an individual. The ICP for dementia is based on best practice and helps to develop a multidisciplinary culture of continuous quality improvement for services and people who care for people with dementia and their families.

Living & Dying Well – Local Action Plan: A local implementation plan for the national action plan of Living & Dying Well.

Long Term Conditions Collaborative: The Collaborative is designed to help people to deliver improvements in patient centred services and change the way care is provided for people with long term conditions such as dementia. The Collaborative focused on achieving sustainable improvements in the management of long term conditions across three work streams: Self Management, Condition Management, and Complex Care / Case Management. The Collaborative is designed to support NHS Boards and their partners to deliver a number of targets which involve the care and treatment patients with dementia.

Mental Health Collaborative: The overall aim of the Mental Health Collaborative is to support NHS Fife to make the improvements needed to improve the quality of care received by people with mental health conditions, including dementia, by engaging in a culture of continuous improvement and service development in order to deliver against key national targets set out by the Scottish Government. This will involve linking into and leading on achieving dementia related NHS Health, Efficiency, Access and Treatment (HEAT) targets, including increasing the rates of diagnosis of dementia and earlier intervention.
National Context
Consultation on the Scottish National Dementia Strategy

Better Health, Better Care (2007, NHS Scotland): An action plan outlining the actions the Government will take to improve health. The central themes of the Action Plan are patient participation, improved healthcare access, and a focus on the twin challenges of improving Scotland’s public health and tackling health inequalities.

Better Outcomes for Older People (2005, NHS Scotland): A framework for developing joint services with three functions:
• To promote the implementation and mainstreaming of joint and integrated services by local partnerships.
• To set out the requirements and timescales which the local partnerships of NHS Boards and councils should meet in developing joint and integrated services.
• To act as a tool to assist in the implementation of joint and integrated services.

Clinical Guidance for Dementia (2006, NICE/SCIE): A joint national clinical guideline on the management of dementia. Key recommendations include: integrated working across all agencies; assessment, support and treatment (where needed) for carers; dementia care training for all staff working with older people; and improvement of care for people with dementia in general hospitals.

Delivering for Mental Health (2006, Scottish Executive): The mental health delivery plan for Scotland which sets out targets and 14 commitments for the development of mental health services.

Improving services and support for people with Dementia (2007, National Audit Office): A critical report investigating the quality of care received by people with dementia and their families. It found that the quality of services received was extremely variable, that there were deficiencies in carer support, and that services in the community or care home are not consistently delivering their objective of supporting people to live independently for as long as possible.

Living & Dying Well (2008, NHS Scotland): An action plan to ensure that good palliative and end of life care is available for all patients and families who need it in a consistent, comprehensive, appropriate and equitable manner across all care settings in Scotland. It is intended for all health and social care policy makers, planners and practitioners, and is designed to produce achievable and measurable changes which will ensure quality improvement and enhance patient and carer experience.
Management of Patients with Dementia – A National Clinical Guidance (2006, Scottish Intercollegiate Guidelines Network): The guideline considers investigations and interventions in which direct benefit to the patient with dementia can be demonstrated. SIGN evaluates research using a hierarchy of evidence to weight studies in an effort to form reliable clinical guidelines. SIGN recognises the overall lack of high quality research for people with dementia, and the difficulty in using small or quantitative studies as a means to issuing guidance.

Delivery Framework for Adult Rehabilitation: The Frameworks focus on improving effective management of long term conditions such as dementia through providing early intervention, diagnosis and rehabilitation are important to people with dementia, especially those living at home.
This Strategy has been produced as part of a Knowledge Transfer Partnership between Fife Council, NHS Fife and the University of Stirling’s Dementia Services Development Centre.