

Report To: Community Health & Care
Partnership Sub Committee

Date: 9th January 2014

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Report No:
CHCP/03/2014/SMcCR

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Subject: WORKING TOWARDS A DEMENTIA FRIENDLY INVERCLYDE:
INVERCLYDE'S DEMENTIA STRATEGY

1.0 PURPOSE

- 1.1 To update the CHCP Sub-Committee of progress in respect of the Inverclyde Dementia Strategy and to specifically consider the following;
- i. Consultation feedback
 - ii. Final Strategy and Implementation Plan
- 1.2 To build on previous reports to the CHCP Sub-Committee, update the position in relation to Inverclyde's response to Scotland's First National Dementia Strategy, 2010 and set this in context with the publication of Scotland's Second National Dementia Strategy 2013.
- 1.3 To advise the CHCP Sub-Committee of the feedback from the public consultation in respect of Inverclyde's Draft Dementia Strategy and proposals for the implementation of the Strategy.

2.0 SUMMARY

- 2.1 The Sub-Committee received a report in February 2013 in respect of the development of a local Dementia Strategy for Inverclyde.
- 2.2 Inverclyde's Draft Dementia Strategy and Consultation were launched in April 2013; the consultation period was extended until the end of August 2013 to allow more time for feedback.
- 2.3 Feedback from the consultation indicated that the draft strategy had been well received with wide ranging support for the emphasis for people with Dementia to live and participate fully and actively in the community. Suggestions were received for more detailed references and linkages being made with other Council wide strategies. Suggestions were also made about developing targeted awareness raising campaigns both among agencies, professionals and within the broader community to embed good practice and support promotion of a 'Dementia Friendly Inverclyde'.
- 2.4 The consultation responses relate to the need to focus on the following areas:
- Involvement and Consultation arrangements
 - Communication strategy - communication materials

- Learning and development
- Linking with other strategies
- Promoting a Dementia Friendly Inverclyde

2.5 These themes will be addressed through incorporating the feedback from the consultation within the more detailed implementation plan. This will be done by setting up work streams through relevant subgroups to develop and implement actions and further embed good practice in dementia care.

2.6 The aim will be to accelerate action to:

- Promote a Dementia Friendly Inverclyde
- Promote Excellence- education, learning and development.
- More emphasis on Housing, design how adaptations, Telehealthcare and Reablement can support people with Dementia in the community.
- Continue to build on what we are doing.
- Have a focus on community development.

3.0 RECOMMENDATIONS

3.1 The CHCP Sub Committee is asked to note the ongoing work and progress being achieved in respect of the Inverclyde Dementia Strategy and developments and proposals as set out in this report.

3.2 The CHCP Sub Committee is asked to endorse Working Together Towards a Dementia Friendly Inverclyde, the Inverclyde Dementia Strategy for 2013 -16, and the Implementation Plan (Appendix A).

3.3 The CHCP Sub Committee is asked to support the investment of £70,000 as outlined in para 5.2 to implement the Dementia Strategy (Appendix B).

3.4 The CHCP Sub Committee is asked to receive annual reports on the updating of the Strategy and Implementation Plans.

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Partnership

4.0 BACKGROUND

The CHCP Sub-Committee has received reports on the requirements of Scotland's National Dementia Strategy, 2010 with updates on Inverclyde's response in 2012 and 2013. Local work has been informed by two key areas for service delivery change in respect of improving support after diagnosis and improving care within general hospital. The first national strategy emphasised change across the whole system of health and social care to improve our work with people and dementia and their families

4.1. The second national Dementia Strategy for Scotland was published in June 2013.

The Strategy is continuing with work already underway from 2010, with a greater emphasis on the following areas;

- Consolidate and build upon the work taken forward since 2010;
- Identify areas where extra support and leverage are needed to support service transformation; and
- Promoting Dementia Friendly Communities

4.2 The national strategy describes three main challenges which will continue to require to be addressed over the next three years. These are:

- Care and support to people with Dementia and their families and carers must be offered in a way which promotes wellbeing and quality of life, protects their rights and respects their humanity.
- Continue to improve services and support from when someone presents for diagnosis throughout the course of the illness including support for carers.
- There is an ongoing expectation that the process of service redesign will ensure care and support people with Dementia are at the heart of effective services delivered.

4.3 The key outcomes for the second national strategy are defined as follows:

- more people with dementia living a good quality of life at home for longer
- dementia-enabled and dementia-friendly local communities that contribute to greater awareness of dementia and reduce stigma
- timely, accurate diagnosis of dementia
- better post diagnostic support for people with dementia and their families
- more people with dementia and their families and carers being involved as equal partners in care throughout the journey of the illness
- better respect and promotion of rights in all settings, together with improved compliance with the legal requirements in respect of treatment
- people with dementia in hospitals or other institutional settings always being treated with dignity and respect

4.4 The Inverclyde Dementia Strategy was written to reflect progress already made in relation to meeting key elements of Scotland's First National Dementia Strategy and in anticipation of key elements now included in the Scottish Government's Second National Dementia Strategy.

The Inverclyde Strategy has a strong emphasis on promoting dementia friendly communities and was written with reference to other strategies in respect of health and social care extending to arrangements that require to be put in place through community planning and the single outcome agreement to enhance the focus of our strategy to progress work within the community and make dementia a priority with more services and partners.

Therefore Inverclyde has adopted an approach which is consistent with national directions. This puts Inverclyde in a good position going forward.

4.5 The Dementia Strategy Working Group has had a pivotal role in developing Inverclyde's Dementia Strategy. Membership of both the working group and Forum is being reviewed. The working group will become an implementation group and subgroups will be established to take forward the following themes arising from consultation on the draft strategy:

- Involvement and Consultation of people with Dementia, carers and the public
- Communication strategy including accessible communication materials and leaflets
- Learning and development to aid understanding of Dementia
- Linking with other strategies so every policy has an impact for Dementia perspective
- Promoting a Dementia Friendly Inverclyde in every aspect of life locally

A report on the consultation is available which explores the key themes to emerge from the consultation requiring a shift in focus as outlined above (Appendix A).

4.6 Over the summer members of the existing working group, including community representatives, pursued the following which were aimed to inform the group of best practice and develop specific proposals and actions for development and implementation of the strategy which reinforced some key messages arising from the consultation feedback, aligned to national directions. Examples of work reinforcing these messages are as follows:

4.6.1 **National Housing and Dementia Events**

Organised jointly between the Scottish Government, Chartered Institute for Housing and the Joint Improvement Service. This aligns with work to develop a CHCP Housing and Accommodation Strategy, and inform work to engage with local Registered Social Landlords. This will allow us to raise the profile of housing and dementia and is aligned to our intentions stated within the CHCP Commissioning Strategy to provide care and support at home or in more homely environments, raising the profile and interface required on housing, health and social care more widely.

4.6.2 **Dementia Friendly Communities**

Members of the group have visited projects to learn from experience from other areas to develop a proposal to promote a dementia friendly Inverclyde. Community representatives have provided examples that could be built upon within Inverclyde. Suggestions include consideration of:

- A dementia friendly award scheme and enlisting support from corporate communications in design of materials and website development for general information and communication about services and resources, as well as specific awareness raising campaigns through creation of a communication plan, timeline and planner.
- Creating events like Dementia Awareness week.
- To develop guidance for the Council on developing Dementia Friendly Communities, setting a standard linked to national guidance for Local Government; this will be taken forward through the revised dementia forum and working group, which will become an overarching implementation and review group.

4.6.3 These examples could provide the potential to lever in support from local businesses and harness wider engagement of organisations to become involved with the strategy. This concurs with recommendations within the Scottish Government's Second National Dementia Strategy.

4.6.4 **Interface with Mental Health- Recovery, Inclusion and Regeneration**

This is aligned to work currently progressing to scope the potential of a proposal with third sector partners; a key element of this work includes people with dementia, their families and carers. This will involve an event early 2014 involving key people across the Council to reinvigorate elements of our existing commitments for mental health and wellbeing, with a community focus support.

4.6.5 **Single Outcome Agreement**

Work is underway to develop a proposal which will engage more partners through community planning arrangements and align with the outcomes identified within the Single Outcome Agreement. This is important as Inverclyde's Dementia Strategy and the commitment to work towards a dementia friendly Inverclyde require a corporate approach.

4.6.6 **HEAT Target Post-Diagnostic Support**

The Scottish Government remains committed to HEAT targets, in particular the target introduced in April 2013. This requires NHS Boards:

“To deliver the expected rates of dementia diagnosis and, by 2015/16, which is that all people newly diagnosed with dementia will have a minimum of a year of post diagnostic support coordinated by a link worker that will lead with service users and carers the building of a person centred support plan”.

4.6.7 Inverclyde CHCP has progressed this work through the employment of a Dementia Link Worker for an initial 12 months supported by Reshaping Care for Older People Change Fund. The Link Worker is employed by Alzheimer Scotland and is based within the Older People's Mental Health Team.

4.6.8 An evaluation of this initiative has concluded that the provision of post diagnostic support will be required as a discrete element of the care pathway for people with dementia, their families and carers.

4.6.9 There has been no new funding allocated to Local Government to specifically implement the Dementia Strategy and existing developments have been achieved through the Reshaping Care for Older People Change Fund and the redesign of older people's mental health services. However, £70,000 has been identified from the CHCP Independent Living Fund, which provides the opportunity to maintain and take forward key elements of the strategy as outlined in Section 5.

5.0 **PROPOSALS**

5.1 Implementing the Inverclyde Dementia Strategy

The Dementia Strategy Working Group will become an implementation Group, with a revised membership informed by the work stream requirements. The Working Group will report to the Inverclyde Dementia Strategy Forum, a wider stakeholder group.

5.2 £70,000 has been identified from the CHCP Independent Living Fund and it is proposed that this funding is used to:

- i. Further develop post-diagnostic support for people newly diagnosed with Dementia
- ii. Develop communication strategy and public information leaflets and learning materials to enhance understanding of Dementia
- iii. Invest in community development worker to support the Dementia Forum and implementation group to undertake community development work to develop dementia friendly community initiatives and peer support networks across Inverclyde

- iv. Launch a Dementia Friendly Community Award Scheme to encourage local businesses to participate in promoting a Dementia friendly approach.

6.0 IMPLICATIONS

6.1 Legal: None.

6.2 Finance:

| Cost Centre | Budget Heading | Budget Year | Proposed Spend this Report | Virement From | Other Comments |
|---------------|----------------|-------------|----------------------------|---------------|--|
| Mental Health | Various | 2014/15 | £70,000 | NA | Funded from Independent Living Earmarked Reserve |

At this stage the detail of spend and associated timing profile is still to be finalised, the indicative areas of spend are expected to be:

- Post Diagnostic Support, to be provided by the 3rd sector £35,000
- Community Development Worker £25,000
- Awareness/ Information/Toolkit/ Award £10,000

6.3 Personnel: None

6.4 Equalities: Improve services and participation of people with dementia, their families and carers within Inverclyde

6.5 Repopulation: The ageing population profile in Inverclyde will increase the prevalence of Dementia.

7.0 CONSULTATION

7.1 This report refers to the consultation undertaken on the draft strategy and refers to how the consultation has influenced and improved the strategy with proposals being brought forward in response to the consultation feedback and in line with national guidance.

7.2 It is intended that there will be ongoing consultation with our community throughout the implementation of the strategy.

8.0 LIST OF BACKGROUND PAPERS

8.1 Inverclyde Dementia Strategy 2013 - 2016

8.2 Scotland's Second National Dementia Strategy June 2013

8.3 Inverclyde Dementia Strategy Progress Report 2012

8.4 Scotland's National Dementia Strategy 2010

8.5 Standards of Care for Dementia, Scottish Government 2011.

8.6 Remember I'm Still Me – Inverclyde Progress Report April 2010.

Working Towards a Dementia Friendly Inverclyde: Inverclyde Dementia Strategy 2013-2016: Consultation Feedback Report.

1. Introduction

This document gives feedback on the responses received to the consultation of the Draft Inverclyde Dementia Strategy and explains how the feedback has influenced the strategy and the changes which will be made as a result of the consultation process.

This report includes a summary of the general themes arising from the consultation feedback.

We would like to thank everyone who has given their time to respond and contribute to this consultation.

2. Background

The aim of the strategy is to ensure significant improvements are made across four key areas and six strategic outcomes.

- Improve Dementia Awareness and knowledge
 - Improving Community Inclusion
 - Early Diagnosis and Support
 - Living Well with Dementia
1. Improve coordination, collaboration and continuity of care across services
 2. Improve access to services
 3. Improve flexibility of services
 4. Improve capacity of services to be responsive
 5. Increase awareness of dementia in the general public and community
 6. Increase opportunities for people with dementia and their families and carers to contribute to service planning

The strategy was launched in April 2013, developed in partnership by the Dementia Strategy Working Group; members of the group were looking to improve dementia care across Inverclyde to plan for the future, anticipating an increase in the numbers of people with dementia, their families and carers within Inverclyde. The drafting of the strategy, adopting an inclusive approach, encouraged participation from a wide range of stakeholders during the consultation process. In particular, enabled the voice of users and carers to be represented which was evident in the design of the programme to launch the draft strategy, with the contributions from people reflecting the lived experience. Followed up by a number of focus groups, facilitated by our partners and third sector organisations.

Members of the Dementia Strategy Working Group recognised that there is a unique opportunity to review current services and generate a system that can work for people with dementia for the future that empowers people with dementia, their families and carers so they are in control, with a system that delivers the outcomes they need.

The strategy was written reflecting progress within Inverclyde since publication of Scotland's National Dementia Strategy in 2010 and anticipated further direction from the Scottish Government with Scotland's Second National Dementia Strategy which was published in June 2013.

3. Overview of the consultation process

On 26th April 2013 Inverclyde CHCP published the draft strategy and consultation. The published document invited all interested stakeholders to comment on the draft strategy to see if the outcomes identified were the correct ones, and invited all interested parties to offer their views on how the outcomes might be achieved.

The formal consultation took place over a sixteen week period involved a range of opportunities for people to contribute as follows.

This report summarises feedback from people who attended the launch event, focus groups or completed a consultation questionnaire.

The launch event hosted 15 round table discussions involving 155 people.

Your Voice (Inverclyde Community Care Forum) and the Inverclyde Carer's Network facilitated 7 Focus Groups involving 54 people.

37 people completed the consultation questionnaire. The questions we asked are available in the Appendix.

246 people contributed to the consultation.

Some respondents consulted the draft strategy and responded independently, some attended the launch event and some did both. Some responses addressed all consultation questions, some addressed points of particular interest. A number of respondents provided feedback from both a personal and a professional perspective whilst some provided feedback in a dual professional representation capacity.

The highest number of responses was received from the third sector (advocates, not providers) and carers. There were 4 responses to the questionnaire from people who identified themselves as a person with dementia. The focus groups reached more people affected by dementia and therefore provides a more balanced response overall to this consultation. Future consultation and engagement work will need to consider more carefully the arrangements required to involve people with dementia to ensure their views are reflected.

4. What people told us: General themes arising from the consultation feedback.

4.1. Raising Awareness and Knowledge

The focus and priority the strategy will bring was welcomed, the need for raising awareness and publicity along with targeted awareness raising campaigns was commented on by the majority of respondents.

Some concern was held regarding capacity of the system with comment that sufficient resources need to be in place with investment in key areas of health and social care, as well as other areas such as housing. The role of public health was mentioned by several respondents.

It was suggested raising awareness in public and professional arenas should form a more developed work stream for implementation.

A number of respondents supported the view that school based educational activity would be beneficial, with the aim of raising awareness of younger people. The need to ensure that campaigns are positive and deliver a message that early intervention and planning can improve capacity to live well with dementia was highlighted.

The place of awareness raising was a re-occurring theme with the aim of encouraging people throughout the life course to recognise and understand the impact of dementia, to enable people with dementia to be treated with dignity and respect. The promotion of inter-generational work was raised as relevant in relation to targeting awareness more broadly within our community.

'Take the time to get to know me, what is important to me and support me, taking account of my changing needs and abilities'.

4.2. Training

The requirement for better training, skills and knowledge across all health and care sectors was raised with a particular focus on accredited training, continuous professional development, undergraduate and post graduate education.

Many respondents commented on the need for good relevant training to be available illustrated by the following example;

'I did not receive any training on working with people with dementia when I was at university which would have helped me in my current role'.

A number of people expressed the view that people with dementia, their families and carers should be involved in training and awareness programmes.

This was supported by the involvement of a member of the Scottish Dementia Working Group, a national campaigning group whose membership is made up of people with dementia, who shared their lived experience at the launch event. Along with a contribution from local people who shared their experience as a family member or carer. Many respondents commented on the importance of involving people with dementia and their families and carers as follows.

'I feel that personal stories and sharing experiences is powerful to help others understand the impact of dementia on a persons life and describe what would make a difference, in a far more effective way than written text could ever achieve'.

Many respondents commented on how powerful and effective the presentations at the launch event were. In considering how staff across a wide range of services could develop the skills to respond more appropriately and effectively with people with dementia, their families and carers.

Training of staff within care homes and home care staff was mentioned frequently with a particular focus on the need to raise the status and pivotal role of staff within these sectors.

4.3. Early diagnosis and Intervention

There was a general consensus that early diagnosis is essential there were questions raised and mixed views as to the process in relation to knowledge and skills development, reflecting a mixed response centring on whether or not practitioners at first point of contact had the skills and knowledge and up to date practice required to be able to recognise the need for early referral.

There was a mixed response to understanding existing referral mechanisms and opening up a debate about the circumstances and conditions in which people currently access services raising the importance of consistency of response. This debate also raised the importance of continuity of care.

The requirement for flexible ongoing support for people with dementia, their families and carers from the point of diagnosis onwards was raised.

Respondents recognised the key role GP's play and expressed a view that there were opportunities for other professionals within GP practices, for example, practice nurses to become more involved in dementia care. Equally comments were received on the potential opportunities and role of health professionals in a wide range of settings to have a role, particularly within general hospitals.

A number of respondents requested the right for family members to have access to GP's for early diagnosis on behalf of the cared for person where a person may be unaware of or in denial of symptoms.

A number of respondents expressed a need to ensure care is taken not to over diagnose.

4.4. Acute Hospitals

A number of comments were received regarding the need for general ward staff to understand the needs of people with dementia, which also relates to point 4.3 above, which relates to developing the care pathway further to enable an appropriate response to the needs of people with dementia in that setting.

4.5. Home Care

Comments received regarding home care were broadly in line with comments received in relation to care homes with regard to quality of care, skills and knowledge of staff.

The need for flexible respite care in a person's home, together with the need for better quality day care. The increased use for example of tele-health care and adapted housing was raised by many respondents.

Some respondents highlighted the need for funding to be more easily accessible to avoid assessment and funding processes becoming a burden to existing responsibilities of carers.

The necessity of carers to be able to take short breaks and respite was strongly voiced.

'Carers need to be aware about the possibility of short breaks, which can be arranged by the Short Breaks Bureau, with the family or having a break from their caring role.'

4.6. Communication and Nutrition

Reduced communication skills and the resultant health implications were mentioned by a number of respondents and anticipated increased role of speech and language therapists and dieticians for staff training purposes and the need for more collaborative working between these specialism's and other health and social care professionals to support people in the community.

A number of responses referred to the need for more joined up working between health and social care professionals to;

'Ensure an individual their family and carers are aware of the range of support available and how to sustain support adopting good practice in care.'

'Family members and carers require information and support in providing personal care to people with dementia.'

5. Responses on areas which require to be strengthened in the strategy

We invited general comments with regard to the draft strategy and respondents used this opportunity to tell us the following;

5.1. Advocacy and legal advice

Some respondents raised the enhanced role of advocacy and legal advice in the context of the need to ensure people engage with future care planning and to afford protection for people who become more vulnerable. The strategy will be adjusted to reflect the role of advocacy and access to legal advice as a result of this feedback.

5.2. Creative Therapies

Respondents were keen to promote the beneficial aspects of creative interaction and increase in the range of activities available to people in a range of settings in care homes and in hospital in particular. Emphasising the positive psychological impact this can have on people with dementia and their quality of life. This point relates to the emphasis in the strategy on inclusion and is discussed further in the following sections.

5.3. Dementia ~Café

Some respondents felt that dementia cafes should be positively encouraged as it was felt they could play a significant role in enabling people with dementia to interact and socialise in a safe, positive and supportive environment.

5.4. Crisis

Crisis support and intervention was raised by a number of respondents with specific suggestions for an Out of Hours Service and support in the evenings which could enable more people to live at home.

5.5. Environment

Most respondents commented that the environment in which a person with dementia experiences has an influence on health and wellbeing, stability and outlook, with many

comments received that a disabling environment can lead to challenging behaviour. A view was expressed that housing and the built environment are of equal importance to the standard of care provided.

'The environment people live in, whether its their own home, care home or hospital should be dementia friendly, encouraging independence'

5.6. Structured Activities

The subject of access to structured and meaningful activities was raised throughout the consultation with many respondents highlighting the benefits of structured activities in the context of community inclusion.

Many statements were made asking for;

'A programme of activities to be made available in a communal environment'

In order to achieve this there needs to be investment in creating a cultural shift dealing with barriers that can limit opportunities for people to participate in the community. Reflected in many comments from respondents as follows;

'We must all work together to address perceptual barriers and stigma people can experience, to create opportunities that enable people to be active participants in the community they live.'

5.7. Carers

Respondents felt strongly that increased respite care services and short breaks should be available. Some respondents commented that an increase in day care opportunities would help ease a carer's workload. Respondents felt there is a lack of information regarding the support that is available to carers. Reinforced with statements like the following;

What does it mean in practice to be on a carers register?

Some respondents felt that a communication strategy is required detailing and promoting services available with local emergency contacts.

A number of respondents commented that existing carer and user support groups were a good source of help and information, but that more support groups, including peer support initiatives, will be required in the future.

5.8. Living Alone

Some respondents commented that there are particular issues in relation to people who live alone which will require further exploration. Issues were raised in relation to access to day care and support services. The importance of transport as part of the infrastructure to support people to participate in the community was highlighted.

Some respondents felt that people with dementia who live alone may be susceptible to greater isolation limiting access to support services. This led to more suggestions for neighbourhood befriending schemes and peer support.

'There needs to be greater emphasis on the reduction of social isolation as a preventative measure and increased opportunities for socialisation'

5.9. Befriending and Volunteering

As outlined above a number of respondents were in favour of promoting the benefits of befriending and volunteer schemes for providing one to one interaction and basic daily support. The importance of these schemes was stressed by many respondents for people who live alone. Some respondents were keen to see the development of a Dementia Friends Scheme to support people to participate in the community.

5.10. Publicity

Respondents were keen to see more localised targeted campaigns to promote the strategy, information and awareness raising and support available. Specific suggestions included website development, communication materials, leafleting, use of media and marking significant events, for example, Dementia Awareness Week. Suggestions were received that in order to promote a dementia friendly community this could be supported with the introduction of a Dementia Friendly Award Scheme.

'more information is required to be available in offices, surgeries and public places like libraries. Followed up by awareness raising through talks, seminars targeted to people of all ages'.

'A Dementia Friendly Award Project could engage local businesses to consider how they provide a service to people with dementia'.

5.11. Specific needs

Most respondents supported the focus on links with other strategies for example people with a learning disability and younger people. Some respondents want to see more detailed reference to the needs of people affected by alcohol related dementia.

5.12. Self Directed Support and Personalisation

Some respondents were positive about the potential of self directed support and the potential opportunities this could bring for people with dementia, their families and carers. Some respondents made specific comments about the strategies focus which give people a lead role in directing and managing their health and care. Having an outcomes approach to support a person in tailoring support in principle was supported.

Some respondents referred to the use of tools like This is me as being crucial to realising the potential of directing a persons support and should be promoted as part of a wider communication strategy.

'Self Directed Support could improve opportunities for choice, autonomy and independence'

6. Developing proposals to promote dementia friendly community

Most of the feedback from respondents commented positively to the concept of a Dementia Friendly Community and the emphasis of the strategy on community inclusion, with many suggestions about how to develop an initiative to promote the concept and make this a reality. Better linkages with community planning and the single outcome agreement will be crucial to this aim.

'The local environment could be dementia friendly with special signage, coloured paving and banisters to help people find their way about. specially designed public gardens, providing industries such as the retail industry with information and guidance and how they can provide a service to people with dementia'.

Many suggestions were received on elements of a dementia friendly community. With a general consensus of the model adopted within the draft strategy. Suggestions ranged from dementia friendly design, access to facilities and amenities, open spaces, increased range of venues and activities people can participate along with a proposal for a dementia friendly award scheme to enhance partnership and involvement of local businesses. A proposal will be developed building on the proposed model within the draft strategy.

'There needs to be presentations undertaken in schools, community centres along with Dementia Friendly Community promotions'

7. Conclusion

The draft strategy was well received with the overarching structure, aims and outcomes identified within the strategy viewed positively by many respondents.

There have been a number of important suggestions on how the proposed strategy could be improved. The areas outlined in this feedback report will be given greater prominence and will be incorporated into the final strategy and implementation plan.

Respondents expressed the need for the strategy to be properly funded, and information on how services will be delivered through the number of redesign of services people were aware of was already taking place. Questions were raised as to what this would mean in practice, there was support for an outcome focus as follows,

'By adopting an outcomes approach based on recognising my autonomy and right to make choices while I am able to express an opinion'.

Respondents were supportive of the focus and linkages with other strategies and were keen to see more detail in the implementation and action plan.

This will be achieved by bringing forward proposals to consolidate and build upon work taken forward since 2010. Identify areas where extra support and leverage is required to support implementation and more specifically proposals to support promotion of a dementia friendly Inverclyde.

8. Summary

The consultation feedback received can be grouped under the following headings which will support development of the work streams required to implement the strategy;

- Engagement and involvement of people with dementia, their families and carers.
- Development of a robust Communication Strategy and Action Plan.
- Creating more learning and development opportunities along with a Skills and Knowledge Action Plan, involving people with dementia, their families and carers.
- Promoting joined up work to facilitate action and links with other strategies, translating these into more tangible outcomes for people with dementia, their families and carers.
- Taking forward specific proposals to promote a Dementia Friendly Inverclyde.
- Ensure implementation of Promoting Excellence is evidenced across a range of settings.

- A particular focus on the environment will be developed, including Housing, design and tele-health care, re-ablement, managing transitions and support.
- Undertake an impact assessment on the strategy and proposals with a particular focus on the costs and benefits in several areas of work underway within the existing strategy and more specifically utilising research and best practice aligned to national developments applied to the local context. This recommendation was illustrated by the following comment.

‘Future budgets, policies and services should be screened in respect of the impact on people with dementia, their families and carers’.

Following the consultation feedback we will adjust the strategy and increase the recommendations within the objectives to reflect the comments made by people who contributed throughout the consultation period and reflected in this report.

13th November 2013

Working Towards a Dementia Friendly Inverclyde

Inverclyde Dementia Strategy 2013-2016



Forward

We are committed to working towards a dementia friendly Inverclyde.

Most people will know somebody who has dementia, either a member of their family, someone in their neighbourhood or wider networks. Some people will spend time in hospital, nursing home or residential care, many people with dementia will live at home. The more people with dementia can remain engaged with their communities, using their skills and their confidence, the better their quality of life will be. This also supports their continuing contribution to our community.

Communities that are dementia friendly have more opportunity to support people in the early stages of dementia, maintaining and boosting their confidence and their ability to manage everyday life.

What is good for people with dementia is good for everybody. Places and neighbourhoods that provide good housing transport and facilities will not only be more dementia friendly, but will also make life easier for everyone.

The number of people living with dementia in Inverclyde will increase over the next 20 years. This is due to an aging population, lifestyle factors and improvements in identifying and diagnosing dementia. At 2013 in Inverclyde there are 1385 people predicted to have dementia. Dementia mainly affects older people however, it can affect younger people and in Inverclyde there are 49 people under the age of 65 predicted to have dementia.

We know dementia increases with age and in the context of the demographic changes across Scotland's whole population there is a strong national focus on the needs of people with dementia, their families and carers. We have worked towards recommendations and directions set out in Scotland's National Dementia Strategy, published in 2010 and this strategy incorporates additional priorities and actions anticipated in the second national strategy to be published later this year.

There is considerable work being undertaken within the Inverclyde Community Health and Care Partnership through a range of change programmes which will have an impact on people with dementia, their families and carers. This strategy will seek to influence these change initiatives in order that a coordinated approach is achieved to maintain our commitment to people with dementia, their families and carers.

This strategy and high level action plan builds on work well underway in Inverclyde, and aims to raise the profile of dementia as a strategic concern, which seeks to promote inclusion and improve outcomes for people with dementia, their families and carers throughout the lifespan. We are basing the strategy on key outcomes for people with dementia, their families and carers. We have identified four themes on which the action plan is based, and identified areas of improvement work which will help deliver our outcomes.

The overarching aim of the strategy is to ensure that our community embraces people with dementia, and services are developed which have direct relevance to people with dementia, providing care and support appropriate to need and demand.

It is recognised that services need to be flexible, local and delivered by appropriately skilled and supported staff to ensure a good quality of life for people with dementia, their families and carers.

There are many things that can be done to support people with dementia to remain independent and participate in a range of activities to contribute as active citizens. Our challenge is to create the opportunities to enable people to live well with dementia. We recognise that this strategy will be a dynamic process.

The strategy was launched in April 2013, developed in partnership by the Dementia Strategy Working Group; members of the group were looking to improve dementia care across Inverclyde to plan for the future, anticipating the increase in the numbers of people with dementia, their families and carers within Inverclyde. The drafting of the strategy, adopting an inclusive approach, encouraged participation from a wide range of stakeholders during the consultation process.

On 26th April 2013 Inverclyde CHCP published the draft strategy at a launch event in Greenock Town Hall. The event enabled the voice of users and carers to be represented with contributions from people reflecting the lived experience. The published document invited all interested stakeholders to comment on the draft strategy to see if the outcomes identified were the correct ones, and invited all interested parties to offer their views on how the outcomes might be achieved.

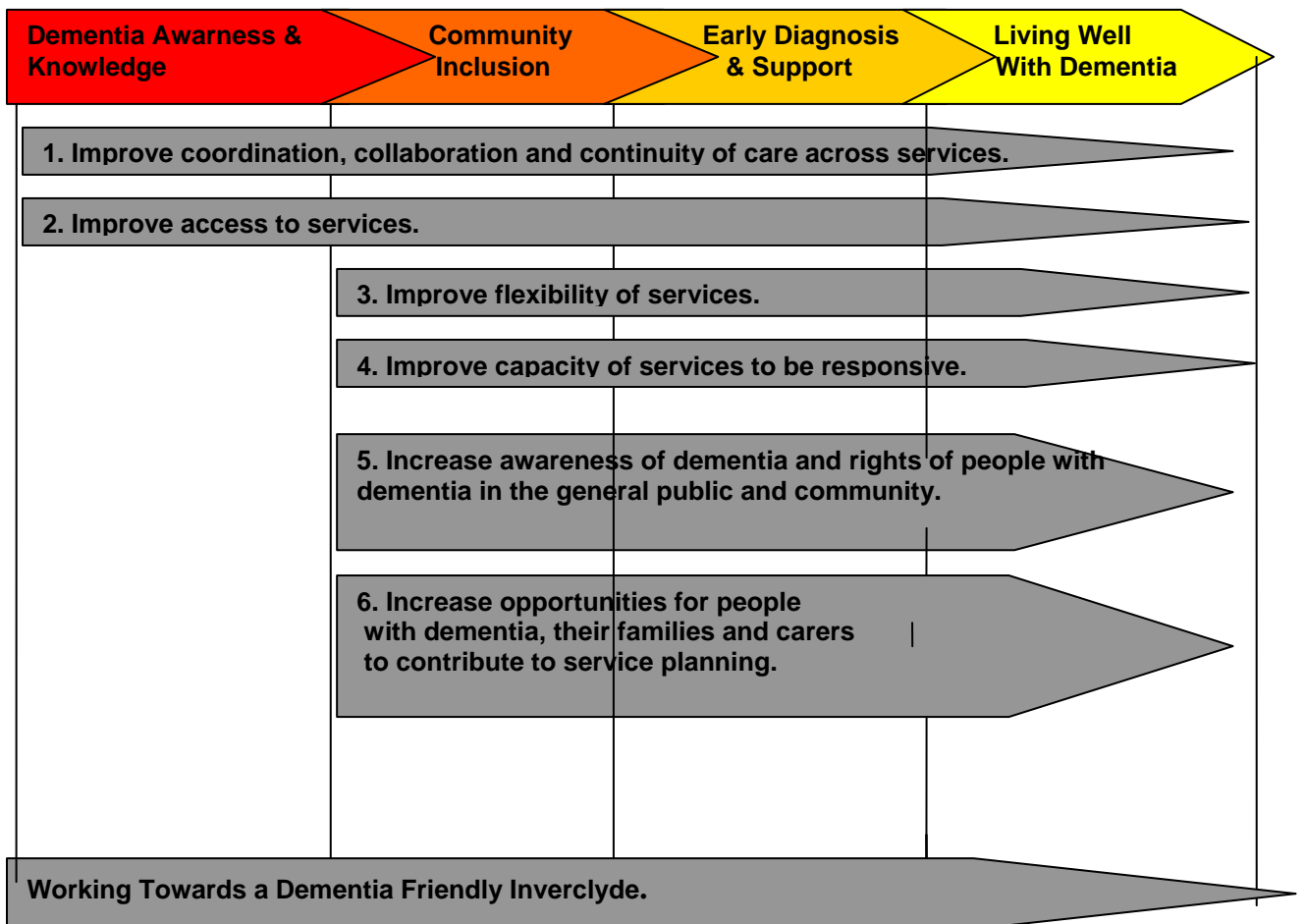
The formal consultation took place over a sixteen week period involved a range of opportunities for people to contribute. This included direct responses to a survey, and via a number of focus groups, facilitated by our partners and third sector organisations.

We would like to thank all those who have shared their experiences and ideas in developing Inverclyde's Dementia Strategy, and who responded to the consultation.

The Dementia Strategy and action plan will be taken forward through the Dementia Strategy Forum Implementation working group.

**Inverclyde Dementia Strategy Forum Working Group.
November 2013**

Getting It Right for People with Dementia, their families and carers in Inverclyde



Contents

| | <u>Page</u> |
|--|--------------------|
| Forward | 2 – 3 |
| Getting It Right for People with Dementia, their families and carers in Inverclyde | 4 |
| Contents | 5 |
| 1. Introduction | 6 |
| 2. Aim of the strategy | 7 |
| 3. Why do we need a strategy | 7- 9 |
| 4. Context | 9 – 10 |
| 5. What we are doing in Inverclyde | 11 – 13 |
| 6. What we intend to do | 13 – 14 |
| 7. Strategic Outcomes | 14 – 15 |
| 8. Linkage to other work and developments that support Outcomes | 16 – 20 |
| 9. Consultation and involvement | 20 |
| 10. Implementation, monitoring and review of the strategy | 20 |
| Dementia Action Plan | 21 – 24 |
| Glossary | 25 – 26 |
| Appendices | |
| Appendix 1. Dementia and incidence | 27 – 28 |
| Appendix 2. Local and National Policy Context | 29 |
| Appendix 3. Reshaping Care for Older People | 30 - 31 |
| Appendix 4. Dementia Care Pathway | 32 – 34 |
| Appendix 5. Charter of Rights, and Standards of Care for People With Dementia, their family and their Carers in Scotland 2009 | 35 – 38 |
| References and links | 39 - 40 |

1. Introduction

The Community Planning Partnership vision for Inverclyde is Getting It Right for Every Child, Citizen and Community. This means the Inverclyde Alliance will work in partnership to create a confident inclusive Inverclyde with safe, sustainable, healthy, nurtured communities and a thriving prosperous economy, with active citizens who are resilient respected and responsible and able to make a positive contribution to the area.

The aim is that our communities are more capable and resilient and are co-producers in achieving positive outcomes for themselves, moving away from dependency to self reliance.

The Single Outcome Agreement and partnerships are committed to

- All older people living in Inverclyde have healthy, productive, active and included lives preferably living in their own homes with access to the services they need, when they need them
- All our communities have good mental health and wellbeing integral to the achievement of all the local outcomes for Inverclyde.
- There is high level political commitment to working towards a Dementia Friendly Inverclyde.

We intend to develop specific elements of the single outcome agreement to raise the profile of people with dementia, their families and carers. Taking a wider perspective, community capacity building will enable people to avoid social isolation and live more independently.

On this basis this strategy sets out Inverclyde's response to Scotland's National Dementia Strategy. Its purpose is to outline what services for people with dementia, their families and carers exist at present, what we want to develop, identifying where we think there are gaps.

The Inverclyde Dementia Strategy Forum, established in 2012, includes a wide range of statutory, non-statutory representatives, within its membership. We have drawn on the experience and knowledge from forum members in developing this strategy and action plan. The action plan has been developed in partnership to ensure the specific needs of people with dementia, their families and carers are articulated and represented. The Inverclyde Dementia Strategy Forum will continue to have a lead role in helping to develop the services and increase knowledge and skills regarding dementia within Inverclyde.

In January 2013 the Inverclyde Dementia Strategy Forum spent the day as a group to consider the needs of people with dementia their families and carers in Inverclyde. The outcome of the event evolved into this outline strategy document. Our strategy is based on a whole system understanding of the inter-relationship between the

services and the support people with dementia, their families and carers need and receive, in context of the community in which we live.

2. Aim of the strategy

The primary aim of the strategy is to ensure that significant improvements are made to the lives of people with dementia, their families and carers.

The strategy is underpinned by 4 objectives and 6 strategic outcomes, which will contribute to influencing action on dementia.

- Improve Dementia Awareness and Knowledge
- Improving Community Inclusion
- Early Diagnosis and Support
- Living Well with Dementia

1. Improve coordination, collaboration and continuity of care across services
2. Improve access to services
3. Improve flexibility of services
4. Improve capacity of services to be responsive
5. Increase awareness of dementia in the general public and community
6. Increase opportunities for people with dementia, their families and carers to contribute to service planning.

Our Commitment to Older People Living in Inverclyde

Our commitment to Older People living in Inverclyde, as set out in the Inverclyde Community Health and Care Partnership Older People's Strategy, is that they should:-

- Feel valued and respected as part of their community
- Be able to live a full and active life in safe and secure surroundings
- Have every opportunity to remain independent, to have freedom of choice and control over how they live their lives
- Be treated with dignity, courtesy and consideration
- Get timely access to the right level of support, information and intervention at times of crisis or transition

The belief that most people, including those with complex care needs, can and would prefer to be supported in their own homes underpins this commitment.

3. Why do we need a strategy?

The development work being undertaken in respect of dementia is informed by Scotland's National Dementia Strategy, which was published by the Scottish Government in June 2010. This was a three year strategy which identified the challenges and key actions to support change to improve the outcomes for

people with dementia and their families. Within this two key areas for service delivery change were prioritised to improve support after diagnosis and improve care within the general hospital. The strategy emphasises the need for change across the whole system of health and social care to address these challenges.

The Scottish Government's second National Dementia Strategy is due to be published later this year. We anticipate the Scottish Government will consolidate work taken forward since 2010, and identify areas where extra support and leverage is needed to support service change. With an increased focus on:

- Health improvement
- Supporting people to live independently
- Nurturing dementia friendly communities and
- Safe, appropriate and dignified care in hospital and care homes

Since the publication of the national strategy the Scottish Government has published national documents to support the action for change in relation to dementia care. The Standards for Care for Dementia in Scotland were published in 2011. These standards relate to everyone with a diagnosis of dementia in Scotland, regardless of where they live, their age, the supports they receive or the severity of their illness. Based on the Charter of Rights for People with Dementia and their Carers in Scotland, 2009, the standards were developed to help people with dementia understand their rights, and how these rights can help make sure that they receive the support they need to stay well, safe and listened to. [Appendix 5.]

Promoting Excellence: A framework for health and social care staff working with people with dementia, their families and carers was published in June 2011. The framework outlines the skills and knowledge health and social care staff should have depending on the role they play in supporting people with dementia. In order to ensure continuing improvement in the care provided and received, the framework needs to work in conjunction with the standards for care.

The strategy emphasises the expectation that partnership working at national and local level would develop further to deliver the objective of transforming dementia services. Within Inverclyde the existing partnership work has been enhanced with the implementation of the CHCP.

HEAT targets and performance:

In order to support the improvement work for people with dementia, their families and carers, the Scottish Government has introduced HEAT targets specific to dementia. The purpose of these targets is to focus NHS Boards on key priorities and measure how these are being achieved.

In 2008, pre the National Dementia Strategy, a target was introduced to identify people with dementia living within our community:

“From April 2008 each NHS Board is required to deliver agreed improvements in the early diagnosis and management of patients with dementia by March 2011.”

This target established the need for dementia registers within GP practices, and the requirement to review these people within 15 months of diagnosis.

In addition in January 2010 Greater Glasgow and Clyde Health Board introduced a local improvement measure within mental health services, to ensure people receiving a diagnosis were provided with appropriate information about the condition.

In 2012 the Scottish Government made a commitment to guarantee that people receiving a diagnosis of dementia will be offered a minimum of one year post diagnostic support:

“To deliver expected rates of dementia diagnosis and by 2015/16, all people newly diagnosed with dementia will have a minimum of a year’s worth of post-diagnostic support coordinated by a link worker, including the building of a person-centred support plan”

In respect of dementia the Life Changes Trust will support the Scottish Government’s one year Post Diagnostic Support guarantee by investing in peer support and community connection projects to enable people to live well in their communities. There will also be a focus on supporting the needs of carers throughout the carer journey.

Our strategy will include the development of performance measures in respect of dementia, to enable us to look at progress towards our objectives.

4. Context

The implications of an aging population and the increased incidence of dementia mean that the development of policy and services for people with dementia, their families and carers are affected by the wider policy context.

Developing our response to meet the needs of people with dementia is set in the context of national policy for health and social care. The key themes integral to our approach are:

- Care is delivered as close to home as possible
- Self directed and personalised care
- Delivery of care based on what works
- Carers support and education
- Providing support in the early stages of illness
- Effective collaboration and joint working
- People with dementia are enabled to live independently within their own community for as long as possible

[A list of related policy is referenced in appendix 2]

A significant culture change will be required within both our community and our local services in respect of dementia. People’s perceptions and understanding of dementia will need to shift in order to focus on how services can be delivered to

enable a response which is personal and flexible, and which meets the needs of people with dementia, their families and carers. This needs the whole community to recognise the role they have in enabling people with dementia to live independently and participate in community life for as long as possible.

There will be the need for ongoing engagement with social care providers, community, third sector organisations, local housing associations and housing providers.

What do we mean by a dementia friendly community?

The concept is based on inclusion, building on what people can do and contribute to society. Supporting people to live well with dementia as active citizens has benefits for the person with dementia, their families and carers and for the community.

Communities that are dementia friendly have more opportunity to support people in the early stages of dementia, maintaining and boosting their confidence and their ability to manage everyday life. This involves cultural and attitudinal change within our community towards people with dementia, and developing confidence and skill to enable a person with dementia to maintain daily activities, quality of life and feel comfortable, safe and included.

The Joseph Rowntree Foundation describes an approach to developing dementia friendly communities. The 4 cornerstones model suggests that a dementia friendly community needs some essential building blocks or cornerstones.

Place; how does the physical environment, housing, neighbourhood and transport support people with dementia?

People; how do carers, families, friends and neighbours health and social care professionals and the wider community respond to and support people with dementia?

Resources; are there sufficient services and facilities for people with dementia and are they appropriate to their needs and supportive of their capabilities? How well can people use the ordinary resources of the community?

Networks; do those who support people with dementia communicate collaborate and plan together sufficiently well to provide the best support and to use people's own assets well?

Reference: Crampton, J. Eley, R. Dean, J. Creating a dementia-friendly York. London: Joseph Rowntree Foundation (JRF), October 2012.

Inverclyde has a history of community development, evident by a strong voluntary and community sector. The enhanced role of our community is central to achieving the aims of this strategy.

5. What we are doing in Inverclyde

Inverclyde Community Health and Care Partnership developed an action plan in 2010 which focused on the work streams which are contained within the National Strategy.

- Treatment and improving the response to behaviours that carers and staff find distressing
- Assessment, diagnosis and implementation of an integrated care pathway- improving the journey of people and with dementia and their carers
- Improving the general service response to dementia
- Rights, dignity and personalisation
- Health improvement, public attitudes and stigma
- Implementing standards of care

The Dementia Strategy has been taken forward through the Reshaping Care for Older People and Mental Health and Wellbeing structures. The work has been targeted to improve the interface between mental health and wider services for older people, encouraging all services to consider the needs of people with dementia their families and carers.

The examples of work progressed include:

- Identify levels of training available in dementia; identifying staff groups to train and to what level. Including training for carers.
- Inverclyde CHCP has achieved the HEAT target: 'Making Improvements in the Diagnosis and Management of People with Dementia' by March 2011 through the identification of people with dementia within the dementia register in GP practices. Greater Glasgow and Clyde Health Board is the best performing Health Board in the UK in respect of this.
- Review of existing information, ensuring people receive appropriate educational information relevant at stages of dementia for people with dementia, their families and carers.
- Review of existing approaches to assessment, and use of complementary assessment tools to focus on enabling people with dementia to live safely at home for as long as possible, facilitate effective care at times of transition, including use of advance statements and life story work.
- Fast track mental health assessment with the aim of preventing hospital admission and facilitating appropriate care at home.
- Developments within acute hospital and care home settings to enable appropriate support and care where mental health needs are identified and are changing.

- Enabling access to the Dementia Care Pathway for people whose care is provided in these settings.
- Development of psychological approaches and interventions across services.
- Implementation of Service Impact Assessments of the Standards of Care for Dementia in Scotland and development in services of action plans to meet requirements.
- Inverclyde CHCP and NHS Greater Glasgow and Clyde adopted the Scottish Inter-collegiate Guidelines Network (SIGN 86-Management of Patients With Dementia) and the Planning, Organisation and Delivery of joined up Services for those with Dementia and Their Carers (NHS HDL(2004) 44). This document defines the pathway for people with dementia as pre-diagnosis; diagnosis; post diagnosis; community services; continuing care and coordination and care management. This formed the basis of the 2010 action plan
- Identifying and training a Dementia Champion within the acute hospital. This will support implementation of patient pathways, for people with dementia, in acute hospital settings. The focus is on values, knowledge, skills and training to support the identification of needs and the care and treatment of people with dementia in Inverclyde Royal Hospital.
- NHS Greater Glasgow and Clyde is one of three Health Board areas funded by the Scottish Government to employ an Allied Health Professional (AHP) consultant in Dementia. The focus of the post is on acute care and the role of the AHP.
- Training of all Home care staff within Inverclyde; and the development of an e-learning course about dementia which will be available to the whole community via Inverclyde Council's website.
- The pilot of approaches with Alzheimer Scotland in respect of early interventions to support people with dementia, their families and carers through the Regeneration Fund;
- The provision of post diagnostic support for people diagnosed with dementia and their family, in partnership with Alzheimer Scotland. Inverclyde CHCP is taking forward the commitment to offer a minimum of one years post diagnostic support, through the employment of a Dementia Link Worker. The Link Worker is employed by Alzheimer Scotland, and based within the Older Peoples Mental Health Team. This is currently supported by the Change Fund.
- The redesign of older people's mental health services, incorporating the requirements of Scotland's National Dementia Strategy and the Dementia Care Pathway;
- Piloting of different approaches to supporting people with dementia at home within the local Tele-care development work;

- Our Single Shared Assessment Procedures have been updated to reflect the Community Care Outcomes Framework. Assessment, care planning and review lie at the heart of identifying and improving outcomes for people with dementia, their families and carers.
- Designing improved facilities and delivery of care for people with complex mental health needs who require continuing NHS care. This is the basis of current work which includes redesign and reprovision of services from Ravenscraig Hospital, by 2015.
- The creation of the Inverclyde Dementia Strategy Forum (IDSF), based on the objective of a Dementia Friendly Inverclyde.

The review of our existing plan highlighted the potential to build on existing work and develop our response to promote greater collaboration and co-ordination across partnerships, including health and social care, community planning and the single outcome agreement.

Areas identified include strengthening our focus on the following:

- Further Implementation of the Promoting Excellence Framework, to support a skilled and knowledgeable work force;
- The needs of younger people with dementia;
- The needs of people with a learning disability with dementia;
- Health improvement activity is targeted on interventions and lifestyle changes which may reduce or slow progress of dementia;
- Access to End of Life and palliative care;
- Linking with wider services including housing providers;
- Research and sharing of best practice;
- Developing community capacity, peer support and networks of support.

6. What we intend to do:

In taking forward the strategy we are committed to:

- Enabling people with dementia, their families and carers to take charge of their health and abilities to ensure people experience the best possible quality of life and sense of wellbeing.
- By collaborative work minimise barriers so that people with dementia can receive what they need, when they need it with services working together.

- Delivering services in line with evidence about what works to improve the care for people with dementia, taking into account individual circumstances.
- Adopt an outcomes based approach that recognises a person with dementia's quality of life is affected by a combination of their dementia, physical health, life experience, their relationship with those around them, and the physical environment in which they live.
- Respect the dignity of the individual, treat people with compassion and see people as partners in their care.
- Provide services that recognise the importance of families, friends and networks of support.
- Promote dementia friendly communities to enable the participation of people with dementia, their families and carers in social, educational and community activities.
- Involving people with dementia, their families and carers in the planning, delivery, monitoring and review of services

These commitments will enable us to take forward our aims, objectives and outcomes detailed below.

7. Strategic Outcomes

Outcome 1 Improve coordination, collaboration and continuity of care across services

Collaborative and coordinated working across services will enable people with dementia, their families and carers to receive what they need, when they need it with services working together. This requires us to develop methods to facilitate improved communication and take a holistic approach to meeting need. Further development of single shared assessment and personalised care plans, providing joint training and shared dementia resources will contribute to this outcome.

Outcome 2 Improve access to services

Work in partnership to implement the care pathway for people with dementia, their families and carers. This requires us to clarify routes of referral and criteria for service use, developing gradual and supported introductions to services through transitions, will help to make services more accessible for people with dementia, their families and carers. This will enable a responsive approach to service provision, based on an individual's need.

Outcome 3 Improve flexibility of services

Building on improving access to services, working with care providers, and local community groups to develop alternative models of care will ensure services are

more flexible and better able to meet the needs of people with dementia, their families and carers. Adopting an outcomes based approach, with people with dementia being partners in their care together with their wider networks of support will enable creative approaches to support.

Outcome 4 Improve capacity of services to be responsive

Services which are responsive to the individual needs of people with dementia are provided by individuals and organisations that have a good level of knowledge and skill and have the resources to adapt services to individual needs. Increasing knowledge about dementia will be a key to the success of this strategy, alongside the development of a culture that embraces creative approaches to supporting people with dementia, their families and carers. Methods for achieving this include Promoting Excellence, developing new and utilising current expertise on dementia, and sharing best practice.

Outcome 5 Increase awareness and understanding of dementia and rights of people with dementia in the general public and community

To enable the development of dementia friendly communities requires the participation of people with dementia, their families and carers, and an understanding of dementia, and how it affects individuals. This will encourage help seeking and help offering within our communities, and reduce the stigma and exclusion experienced by people with dementia, their families and carers. Listening to what people say about what makes a difference will enable services to respond better. Using health improvement approaches to enable our understanding of behaviours and lifestyles that contribute to the risk of developing dementia will support preventative work.

Outcome 6 Increase the opportunities for people with dementia, their families and carers to contribute to service planning.

The strategy aims to achieve this by building on current work, to enable people with dementia, their families and carers to contribute to service redesign, through community capacity building and developing our community involvement and engagement mechanisms. This includes demonstrating how we are meeting the standards of care for dementia, self assessment, peer review, and benchmarking. There is a need to mainstream dementia as a community wide issue, where it is everybody's business across all sectors of our community.

8. Linkage to other work and developments that support outcomes

All the work described in relation to wider strategies is governed by the Inverclyde Single Outcome Agreement and the Community Health and Care Partnership Directorate Improvement Plan.

In order to take forward our four objectives, and six outcomes, we have identified key areas of work that are currently underway, and within which there is an opportunity to progress key elements of the Dementia Strategy.

Promoting Excellence

We will develop our strategy to increase skills development, knowledge and awareness raising activity. This will be supported by the implementation of Promoting Excellence and integrating activity within learning and development and workforce development plans. By improving understanding about dementia what it is, what can be done and what the benefits are of receiving an early diagnosis it is likely more people will be able to acknowledge their condition and seek help. In turn all staff in all organisations who work with adults and older people must be informed and educated in a manner that allows them to understand and provide a person centred service for the person with dementia, their families and carers.

Learning and development opportunities must be ongoing as part of personal and professional development. This will include the identification, development and improvement of dementia expertise. Access to educational materials by utilising methods, including new technology ensuring these are widely available within Inverclyde. This work will be aligned with public awareness activity and a communication strategy.

Research and developing a community of good practice

We aim to develop the strategy on evidence of what works. We will endeavour to develop our links with appropriate bodies learning from research to develop practice, for example:

- Scottish Social Services Council,
- NHS Education Scotland,
- Alzheimer Scotland Centre for Dementia and Practice, University of the West of Scotland, Paisley,
- Dementia Services Development Centre, University of Stirling.

This will also link to our learning and development work across the CHCP and our partners.

Developing community capacity, peer support and networks of support

Taking a wider perspective, community capacity building will enable people to avoid social isolation and live more independently. Increasing awareness of dementia in Inverclyde will support people with dementia to maintain their independence for longer and has the potential to reduce the incidence of stigma and discrimination. Community capacity building is a priority as an area of investment through the Reshaping Care for Older People Change Fund.

There are also existing strategies that need to explicitly incorporate the objectives of this dementia strategy:

End of Life and Palliative Care

Inverclyde CHCP has a commitment to working across agencies to establish access to services required for End of Life Care. We aim to build on work underway to enhance care and support for people with dementia that integrates a palliative approach. Care and support is based on planning by the person with dementia their family and carers which is completed following diagnosis and reviewed regularly.

Linking with wider services including housing providers

We need to support people with dementia to access housing options which meets their lifestyle and care needs and ensure they are given appropriate housing choices. Models of housing provision will need to reflect people's requirement for care and support which is delivered at home.

This requires improved joint working between housing providers and care providers to increase awareness of the needs of people with dementia when it comes to building, design, structure and support arrangements. Better use of existing housing alongside new models of housing incorporating for example, use of adaptations, adapted houses and selection of suitable properties to meet individual needs. Ensuring people have access to appropriate housing and support has a role in preventing inappropriate admission to hospital and residential care.

The Local Housing Strategy is the governing strategy to develop our response to housing need and proposals which will include people with dementia, their families and carers will be taken forward in partnership through the CHCP's Housing and Accommodation Subgroup.

Early onset dementia

In the years to come there will be an increase in the number of people with dementia, many of these people maybe under the age of 65 and have unique needs which will not be met by traditional services. This strategy is therefore not age specific and seeks to influence service development to have due regard for the needs of anyone affected by dementia. Early onset dementia is an area which requires further research and development.

Learning disability

There will be an increase in the number of people with dementia with a learning disability. Methods of provision of services will need to change which will enable earlier diagnosis and support with transitions into services to access support care and treatment which is appropriate to need. The Learning Disability Strategy for Inverclyde is currently being reviewed and will be updated to reflect this strategy.

The local Learning Disability Strategy is guided by national policy, "The Same As You" and followed a review of services for people with learning disabilities in Scotland. The main aim of both national and local action is to support people with a learning disability to be included in community life. The local strategy sets out

proposals for developing sustainable models of services for people with complex needs, including dementia.

Health Improvement

The Scottish Government intends to increase its focus on Health Improvement and lifestyle changes which may reduce the incidence or slow progress of dementia in the second national dementia strategy.

Within Inverclyde CHCP there are ten strategies in place for health improvement and health inequalities. We have highlighted the main ones relevant to people with dementia.

There is a focus on anticipatory care and prevention through the Keep Well and Active Living programmes. The nutrition strategy is also relevant to inform healthy lifestyles contributing to prevention.

Health Inequalities

Inverclyde CHCP has agreed a strategic framework to provide local action on the principles set out in the national policy Equally Well. This is one of an interlinked set of policies to reduce poverty and inequality.

Mental Health and Wellbeing

The CHCP is progressing 'Towards a Flourishing Inverclyde' by developing an action plan for 'Making Wellbeing Matter in Inverclyde'. This will ensure peoples mental wellbeing will be improved and sustained. The action plan is targeted for completion in the autumn of 2013. A key focus of 'Making Well-being Matter in Inverclyde' will be the re-establishment of the Inverclyde Anti-Stigma Partnership and that of the awareness-raising activities through the Inverclyde Mental Health Awareness Planning Group and its-sub group the Inverclyde Creative Forum for the annual Scottish Mental Health Arts & Film Festival.

NHS –Healthcare Quality and Clinical Strategies

The Health Care Quality Strategy for NHS Scotland, 2010, is a development of Better Health Better Care which builds on significant achievements made within the NHS over the past few years. It aims to deliver safe, effective person centred care, supporting people to manage their conditions making the patient experience and personal outcomes integral to services.

The strategy aims to address opportunities to;

- Support longer healthier lives for the population as a whole
- Reduce health inequalities
- Improve the health of the increasing older population including people with dementia
- Developing a skilled workforce

A key aim of NHS Glasgow and Clyde's Clinical Strategy is the development of integrated pathways for all patient groups and conditions over the next five to ten years. Through a programme of clinical led service redesign the aim is to deliver the following for patients and the public;

- Safe effective person centred care to every person
- A focus on maintaining good health
- More support to anticipate, prevent and minimise health problems
- More and better care in the home and community settings
- Increase outpatient and day case treatment for most planned hospital care
- Safe, timely admission and discharge for those who require inpatient care
- Reducing avoidable admission to hospital
- More focus on the use of telehealth care to support people to manage conditions at home.

Mental Health Services

The delivery of mental health services in Inverclyde is guided by Scotland's National Mental Health Strategy which sets out 14 recommendations. The Modernising Mental Health Services Inverclyde programme is currently being implemented. In addition there is currently a programme of clinically led redesign work within NHS Greater Glasgow and Clyde, which will further inform clinical service development over the next 5 to 10 years.

Dementia Care Pathway

Using a model for the care pathway based on the clinical Integrated Care Pathway for Dementia will support the delivery of services in line with evidence about what works to improve services of people with dementia. The aim of the pathway is to support all people with suspected dementia to access diagnosis, assessment and ongoing support if required. [Appendix 4]

Carers Strategy

The Dementia Strategy also links closely with Inverclyde Carers' Strategy 2012-15, which sets out the CHCP's commitment to carers in Inverclyde. Carers are recognised by Inverclyde CHCP, as equal partners in the planning and delivery of care and the action plan sets out how the CHCP and its partners will support carers to continue in their caring role. The Carers Strategy identifies the key outcomes, which carers across Inverclyde in a variety of caring situations have identified as being the most important priorities for them.

Inverclyde Commissioning Strategy

A high level joint commissioning strategy for the Community Health and Care Partnership has been developed with actions for services to develop and bring forward commissioning plans.

There will be a shift in the model of care with a focus on prevention and early intervention with a significant effort to ensure that community capacity building is maximised. The range and flexibility of care, support and treatment will need to grow to meet increased needs, expectations and the outcomes desired by people with dementia, their families and carers. By altering models and methods of service provision we aim to provide services which are relevant to people with dementia,

their families and carers in a more effective way. This is anticipated to impact on what services are commissioned for people with dementia.

The implementation of Self Directed Support will also provide an opportunity for people with dementia to create and manage personalised and flexible support plans. This will be implemented from April 2014.

9. Consultation and involvement

We will continue to develop our consultation and involvement arrangements involving people with dementia and their carers in the planning, development and delivery of the strategy. Consultation and engagement will continue to be developed through the Inverclyde Dementia Strategy Forum.

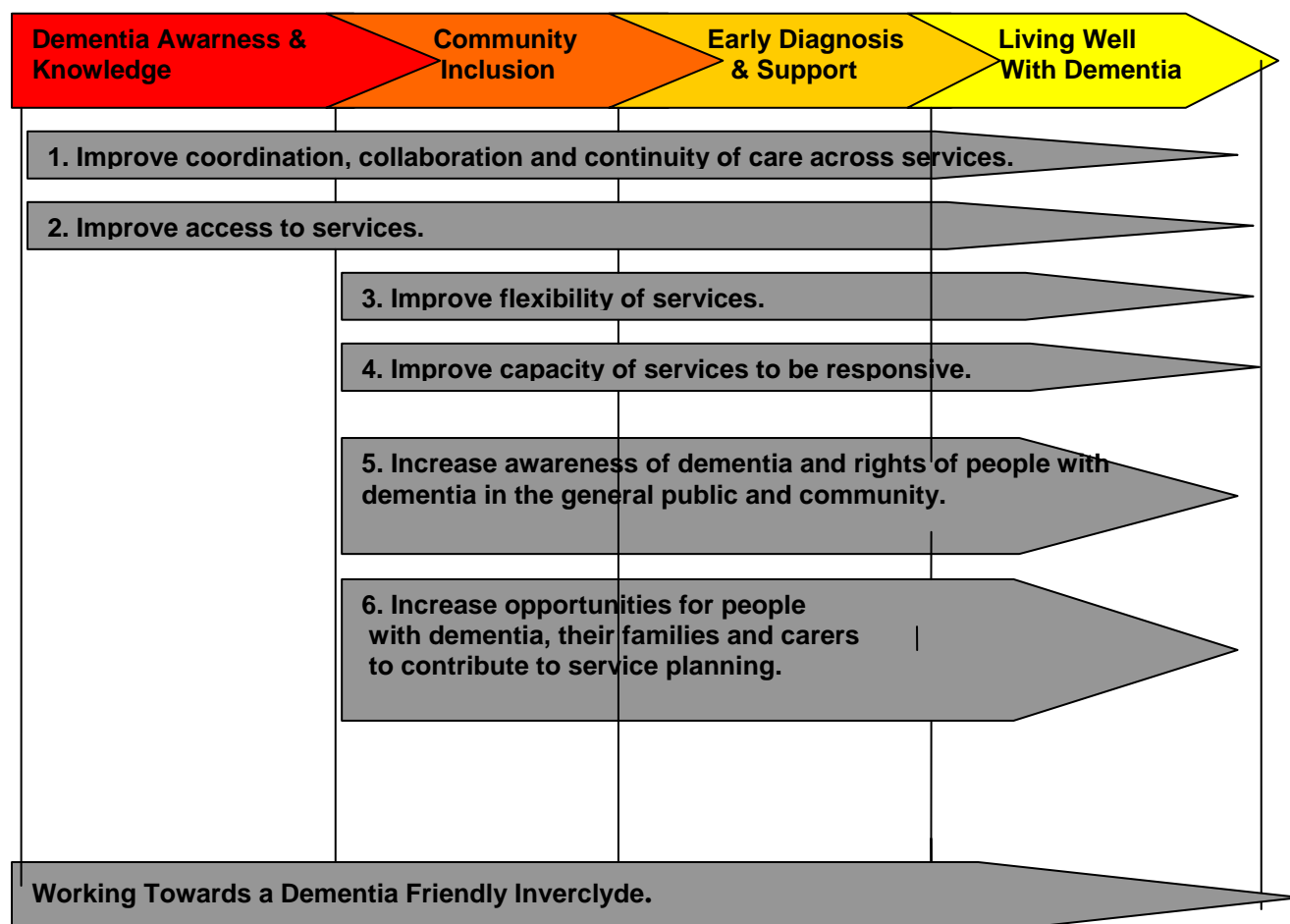
The Inverclyde Community Health and Care Partnership is committed to involving people guided by the CHCP People Involvement Framework. The Public Partnership Forum and CHCP Advisory Group provide a mechanism which will allow for regular gathering of views and feedback.

10. Implementation, monitoring and review of the strategy

The Dementia Strategy will be taken forward through the Dementia Strategy Forum Implementation working group. The Working Group will report to the Inverclyde Dementia Strategy Forum, a wider stakeholder group. The strategy sits within the CHCP governance arrangements for Reshaping Care for Older People as outlined in Appendix 3.

Dementia Action Plan

Getting It Right for People with Dementia, their families and carers in Inverclyde



Crosscutting Themes

1. Improve Dementia Awareness and Knowledge
2. Improving Community Inclusion
3. Early Diagnosis and Support
4. Living Well with Dementia

Strategic Outcomes

Outcome 1 Improve coordination, collaboration and continuity of care across services

Collaborative and coordinated working across services will enable people with dementia, their families and carers to receive what they need, when they need it with services working together. This requires us to develop methods to facilitate improved communication and take a holistic approach to meeting need. Further development of single shared assessment and personalised care plans, providing joint training and shared dementia resources will contribute to this outcome.

Outcome 2 Improve access to services

Work in partnership to implement the care pathway for people with dementia, their families and carers. This requires us to clarify routes of referral and criteria for service use, developing gradual and supported introductions to services through transitions, will help to make services more accessible for people with dementia, their families and carers. This will enable a responsive approach to service provision, based on an individual's need.

Outcome 3 Improve flexibility of services

Building on improving access to services, working with care providers, and local community groups to develop alternative models of care will ensure services are more flexible and better able to meet the needs of people with dementia, their families and carers. Adopting an outcomes based approach, with people with dementia being partners in their care together with their wider networks of support will enable creative approaches to support.

Outcome 4 Improve capacity of services to be responsive

Services which are responsive to the individual needs of people with dementia are provided by individuals and organisations that have a good level of knowledge and skill and have the resources to adapt services to individual needs. Increasing knowledge about dementia will be a key to the success of this strategy, alongside the development of a culture that embraces creative approaches to supporting people with dementia, their families and carers. Methods for achieving this include Promoting Excellence, developing new and utilising current expertise on dementia, and sharing best practice.

Outcome 5 Increase awareness and understanding of dementia and rights of people with dementia in the general public and community

To enable the development of dementia friendly communities requires the participation of people with dementia, their families and carers, and an understanding of dementia, and how it affects individuals. This will encourage help seeking and help offering within our communities, and reduce the stigma and exclusion experienced by people with dementia, their families and carers. Listening to what people say about what makes a difference will enable services to respond better. Using health improvement approaches to enable our understanding of behaviours and lifestyles that contribute to the risk of developing dementia will support preventative work.

Outcome 6 Increase the opportunities for people with dementia, their families and carers to contribute to service planning.

The strategy aims to achieve this by building on current work, to enable people with dementia, their families and carers to contribute to service redesign, through community capacity building and developing our community involvement and engagement mechanisms. This includes demonstrating how we are meeting the

standards of care for dementia, self assessment, peer review, and benchmarking. There is a need to mainstream dementia as a community wide issue, where it is everybody's business across all sectors of our community.

| Outcome | Areas for action | Themes | Linkages/Enabling Work |
|---|---|--|--|
| Outcome 1 Improve coordination and collaboration across services to enable improved continuity of care | <p>Implement training needs analysis across all services, and promote training opportunities</p> <p>Continue to develop use of single shared assessment</p> | <p>Dementia Awareness and Knowledge</p> <p>Living well with Dementia</p> | <p>CHCP Learning and Development plan</p> <p>SWIFT development work</p> |
| Outcome 2 Improve access to services | <p>Implement dementia care pathway, including access from acute services</p> <p>Develop and implement models of post diagnostic support</p> | <p>Early Diagnosis and Support</p> <p>Living well with Dementia</p> | <p>Modernising Mental Health in Inverclyde Carers Strategy HEAT target and standards End of Life and Palliative Care</p> |
| Outcome 3 Improve flexibility of services | <p>Implement asset based and outcome focussed assessment and support planning including Pillars of support models</p> <p>Develop and promote alternative models of care</p> | <p>Living well with Dementia</p> | <p>Self Directed Support</p> <p>Reshaping Care for Older People Strategy</p> <p>CHCP Commissioning Strategy</p> |
| Outcome 4 Improve capacity of services to be responsive | <p>Promote Dementia Champions across services</p> <p>Implement Promoting Excellence Framework</p> <p>Evaluate services using Dementia standards and promote use within</p> | <p>Dementia Awareness and Knowledge</p> <p>Community Inclusion</p> | <p>CHCP Commissioning Strategy</p> <p>Inverclyde Housing strategy</p> <p>CHCP Learning and Development plan</p> |

| | | | |
|---|--|---|--|
| | service development | | |
| Outcome 5 Increase awareness of dementia- in the general public and community | <p>Develop project for promotion of Dementia Friendly Inverclyde</p> <p>Develop communication strategy</p> <p>Promote the charter of rights for people with dementia</p> <p>Develop Health Improvement work to inform and promote lifestyle changes which may reduce or slow the onset of dementia</p> | <p>Community Inclusion</p> <p>Living Well with Dementia</p> | <p>Anti stigma Partnership</p> <p>Single Outcome Agreement</p> <p>Health Improvement; Health Inequalities; Mental Health and Wellbeing</p> |
| Outcome 6 Increased opportunities for people with dementia, their families and carers to contribute to service planning, development and redesign. | <p>Develop consultation and involvement arrangements</p> <p>Sustain and support the development of peer support for people with dementia and their families and carers</p> | <p>Community Inclusion</p> <p>Living Well with Dementia</p> | <p>People Involvement Strategy</p> <p>Carers Strategy</p> |

Glossary

Carers: informal Carers, who may be family or close friends.

Co-morbidity / co-existing: the presence and the effect of one or more disorders or illnesses in addition to the primary disorder or illness.

Dementia: A collective term used to describe a range of progressive conditions that affect mental abilities such as memory, communication and reasoning.

Dementia friendly communities: Positive communities which help people with dementia and their Carer to live their lives as normally as possible for as long as possible, and reduce the stress of isolation.

Demographic changes: Description of how the number and characteristics of people who live in an area are predicted to change over time.

Early intervention: An approach based on detecting and responding to needs and illness as early as possible to aim for better outcomes for people.

HEAT Targets: Scottish government key priorities for NHS services covering:

Health Improvement
Efficiency and Governance improvements
Access to services
Treatment appropriate to individuals

Integrated Care Pathway (ICP) Based on available evidence and guidance, this is a joined up approach to providing services for people with specific needs which identifies what care will be provided, who will provide it, how it will be provided and when it will be provided

Learning disability: A significant, lifelong condition, which includes significant impairment of intellectual functioning (IQ<70) and significant impairment of adaptive and social functioning.

Life Limiting Condition: A wide range of conditions for which there is no reasonable hope of cure.

Long term conditions: Conditions which have a clear diagnosis require ongoing medical care and limit what a person can do for a year or more are generally included e.g. coronary heart disease, diabetes. The definition also includes many conditions which, although long-term and life limiting in some cases, can also be acute or easily managed in others e.g. back pain, skin disorders.

Motor skills: Actions that involve movements of bodily muscles.

Outcomes based: An approach to providing services which focuses on achieving positive results (outcomes) for people with needs.

Outreach: An approach based on bringing and providing services to people at home or where they live or spend time.

Palliative Care: The active holistic care of people with advanced progressive illness including the management of pain and other symptoms and the provision of psychological, social and spiritual support, aimed at achieving the best quality of life for people.

Personalised services / Personalisation: A Scottish Government initiative to allow people to individually tailor their care by giving them more control over health and social care provided for them.

Short breaks (respite): short breaks are provided with the aim of enhancing and developing the quality of life of a person who has support needs and their Carer (where there is one) and to support their relationship. The distinctive feature of a short break is that it should be a positive experience for both. Short breaks can be provided within or out with an individual's home. Short breaks cover all situations including:

- where there is no Carer present, but the person with care needs requires a break from their normal situation
- breaks from caring where the Carer needs a break
- emergency crisis support

Telecare / Telehealth / Assistive Technology: The use of technology to enable individuals to master the tasks at home, increase independence and improve quality of life.

Young onset dementia / early onset dementia: Terms used to describe the diagnosis of dementia in anyone under the age of 65.

APPENDICES

Appendix 1. Dementia and incidence

Dementia is the collective term used to describe a progressive condition with a range of symptoms such as increasing memory impairment, reduced communication skills and reasoning. Alzheimer's disease is the most common. Vascular dementia is the second most common diagnosis. Other types of dementia include Lewy body dementia and Frontotemporal dementia.

The chance of developing dementia increases with age, and it is recognised as a life limiting condition. Dementia is a complex condition which affects people in different ways, symptoms can be difficult to identify and diagnose, particularly when other symptoms or other conditions exist. Dementia can eventually affect all aspects of everyday living, but presents different challenges for the person with dementia, their families and carers at different stages in the illness.

Our aging population will result in a significant increase in the number of people living with dementia in the years ahead. This demographic shift will impact on health, social care, and housing services in particular. There are also implications for wider services in terms of enabling people with dementia to live well and participate in our community.

Population Profile

In Inverclyde there are 1385 people predicted to have dementia. Dementia mainly affects older people however, it can affect younger people and in Inverclyde there are 49 people under the age of 65 predicted to have dementia.

| Under 65 | 65+ | Total |
|----------|------|-------|
| 49 | 1336 | 1385 |

The prevalence rates for older people with dementia aged 65+ is approximately 10% of the older population and an anticipated 30% for people aged over 80. In Inverclyde we anticipate there will be an increase of 10% of those aged 85-89 year with dementia and a 26% increase in those aged 90 or above.

[Data taken from Alzheimer Scotland website Inverclyde data calculated from GROS (General Register Office from Scotland) data applying Euroderm prevalence rates.]

At March 2013 there were 673 people on the Dementia register held within GP practices.

The table below outlines the projected population changes in Inverclyde by age band.

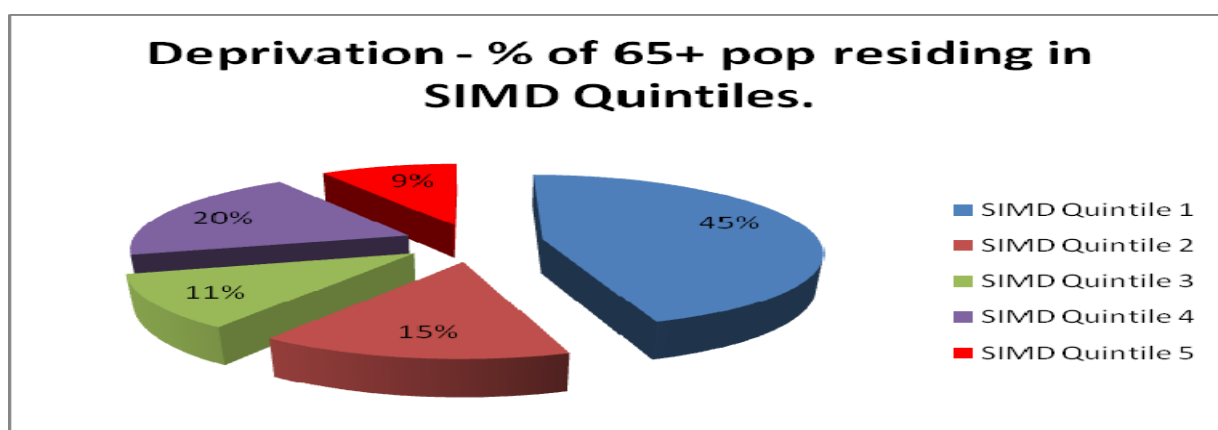
Projected Population Changes in Inverclyde

| Category / Year | 2015 | 2020 | 2025 | 2030 | 2035 |
|-----------------------------|------|------|------|------|------|
| Inverclyde All Ages | -3% | -5% | -9% | -12% | -17% |
| Inverclyde 0-15 | -4% | -5% | -10% | -18% | -27% |
| Inverclyde Working Ages | -2% | -6% | -11% | -18% | -24% |
| Inverclyde Pensionable Ages | -2% | -3% | 1% | 9% | 11% |
| Inverclyde 75+ | 7% | 16% | 31% | 42% | 58% |

The age group in Inverclyde which will increase the most is the 75+ age group. As dementia increases with age, combined with a growing elderly population we anticipate an increase in the prevalence of dementia.

The levels of deprivation within Inverclyde are significant. Many of our highest concentrations of older people live in areas of multiple deprivation, and many live alone.

The graph below shows that 45% of people over 65 living in Inverclyde, live in the Scottish Index of Multiple Deprivation (SIMD) quintile 1, the most deprived. 9% of our older people live in SIMD quintile 5, our most affluent areas.



| | 2009 SIMD Profile | Number | % of entire 65+ pop. |
|----------------|-------------------|--------|----------------------|
| Most Deprived | SIMD Quintile 1 | 6282 | 45% |
| | SIMD Quintile 2 | 2084 | 15% |
| ▲ ▼ | SIMD Quintile 3 | 1568 | 11% |
| | SIMD Quintile 4 | 2743 | 20% |
| | SIMD Quintile 5 | 1322 | 9% |
| Least Deprived | | | |

Appendix 2 Local and National Policy Context

National Policy:

- Better Outcomes for Older People
- Changing Lives
- All our futures: Planning for a Scotland with an Aging Population (2007)
- Shifting the Balance of Care
- Community Care Outcomes Framework
- NHS HEAT Targets
- National Dementia Strategy and Standards for Dementia Care
- National Carers Strategy
- NHS Scotland Quality Strategy 2010
- National Older People's Housing Strategy
- Reshaping Care for Older People: A Programme for Change 2011-21
- Self-Directed Support
- Living and Dying Well
- 2020 Vision

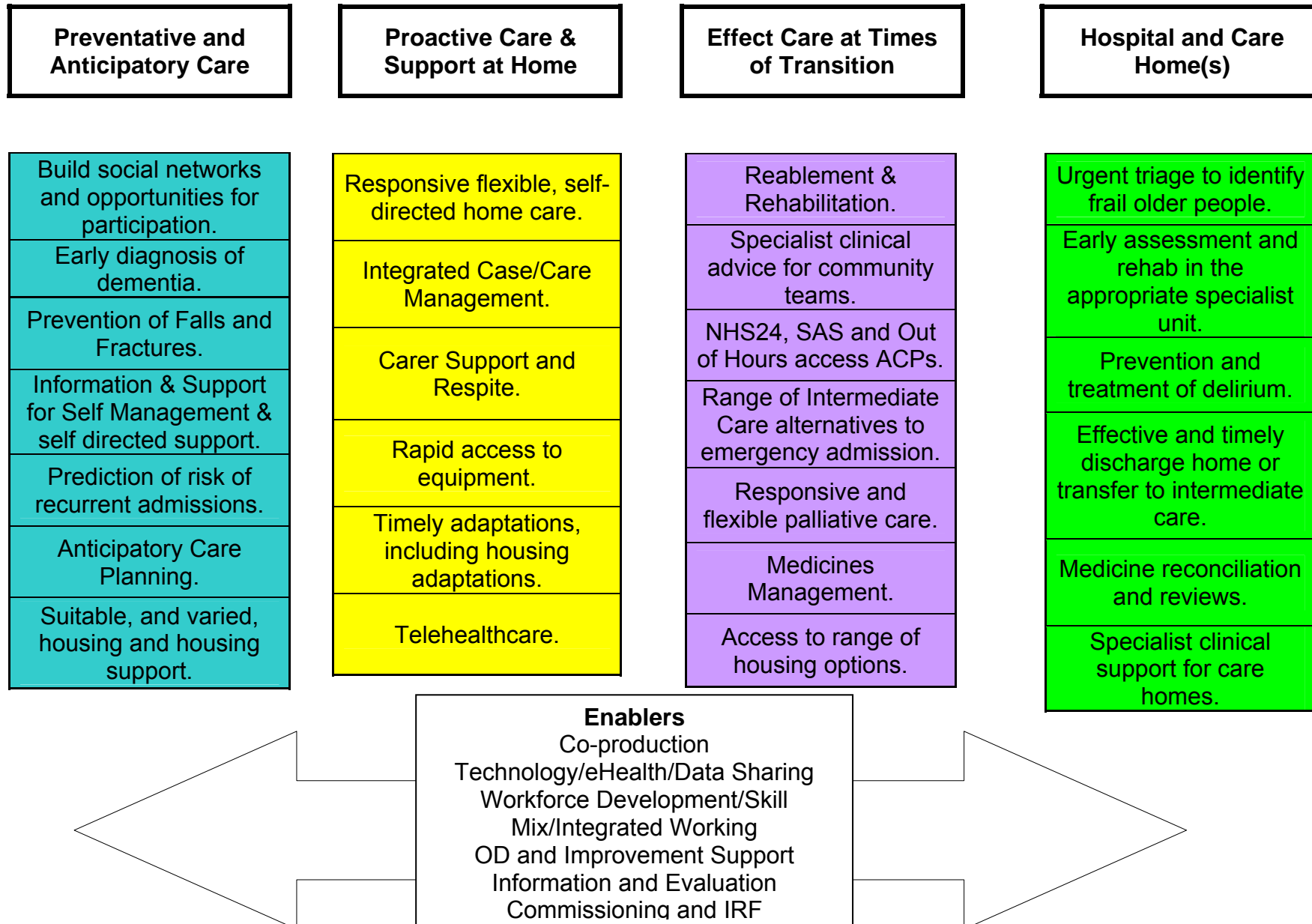
Local Policy:

- Inverclyde Reshaping Care for Older People Change Plan
- Inverclyde Local Housing Strategy
- Inverclyde Carers Strategy 2012 – 15
- Inverclyde Joint Community Care Plan 2010 – 2012
- Inverclyde CHCP Directorate Plan
- NHS GG&C Clyde Mental Health Strategy
- NHS GG&C Long Term Conditions Strategy
- NHS Greater Glasgow and Clyde Planning and Policy Frameworks (Older People/ Disability/ Long Term Conditions/Carers)
- Inverclyde Council Corporate Plan
- NHS GG&C Acute Services Review (ASR)
- NHS GG&C Clinical Services Review
- Inverclyde CHCP People Involvement Framework
- Inverclyde Single Outcome Agreement

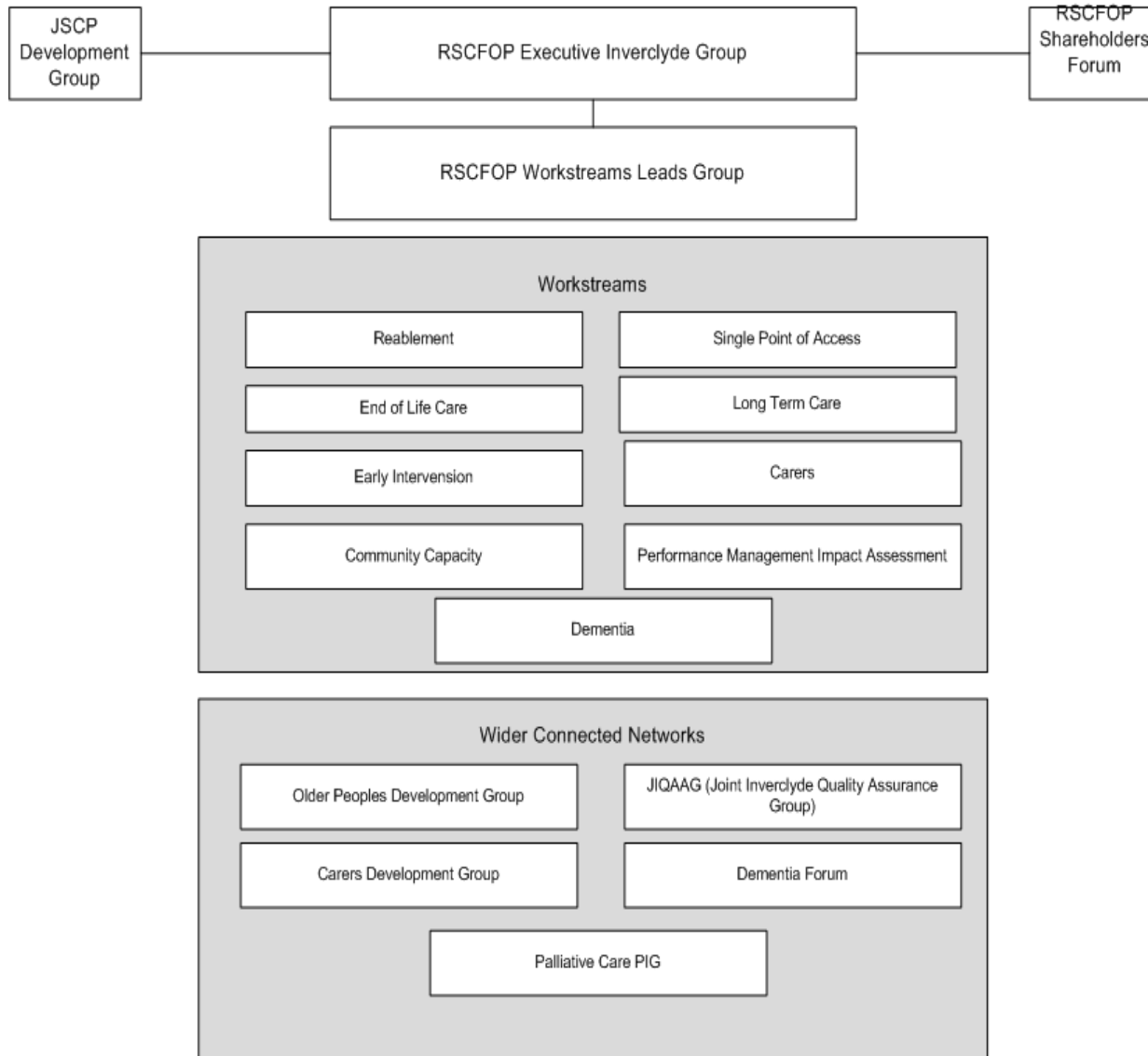
Key Strategic Drivers:

- Reablement
- Integration of health and social care services
- Rehabilitation Framework
- Self Directed Support and Personalisation
- Telecare and Telehealth
- Community Capacity Building/ Community Development
- Co-production – working together with users and carers to develop services and supports

RESHAPING CARE PATHWAY



Governance of the Joint Strategic Commissioning Plan
Reshaping Care for Older People in Inverclyde



Appendix 4. Dementia Care Pathway

Diagnosis

The experience of memory loss can be alarming and frustrating. People whose lives are affected by memory loss need to know if the symptoms are caused by a form of dementia and seek an appropriate medical response. Access to comprehensive diagnostic services is essential to ensure that appropriate advice and support is given to individuals at the earliest opportunity, including access to local services if required.

Post-Diagnostic Support

Access to information and advice will enable people with dementia and their family put in place a support system which can adjust to changing needs at a pace and level which best meets their needs and circumstances. Post diagnostic support enables people to plan for the future, maintain independence and live well with their condition.

Community Services

People with dementia should be supported to maintain a normal life, sustaining family and community relationships. This support should be provided in the home for as long as possible and appropriate.

Access to support is arranged when it is needed and tailored to meet personal choices.

Care in other Settings

There will be occasions where people with dementia can no longer be cared for within the home. When this occurs support will be given to ensure ongoing care is provided within the most appropriate setting be this hospital or care home.

Coordination and Case Management

Services will be provided based on individual need delivered flexibly to take account of changing circumstances. A partnership approach will be taken to assessment, monitoring and review to ensure people with dementia have their needs assessed and services are delivered in a seamless way.

We will make our decision making processes transparent recognising that carers have needs and a carer's assessment will be offered where possible. There will be a named worker for each person with dementia or, where this is not desired, contact routes given.

A Model of Care and Care Pathway For Living Well With Dementia

| Need for help | Interventions | Access | Step up to more intense care when: | Level of Care/ Intensity of care | Service users can expect | People living with dementia should be able to say: |
|--|---|----------------------------------|---|--|---|--|
| Raising awareness and understanding <ul style="list-style-type: none"> to encourage help seeking and help offering Prevention | Dementia awareness Dementia risk reduction Anti stigma | Everyone | Service user chooses | 1. Public Community mental health and well being | To define Living Well with Dementia goals between user/carer & service | Progress towards personal and quality of life goals for living well with dementia <p>I was diagnosed early</p> <p>I and those around me & looking after me feel well supported</p> <p>I have a personal plan to help me to:</p> <ul style="list-style-type: none"> Understand the illness and manage the symptoms Support community connections Access peer support Plan for future care Plan for future decision-making |
| Anyone concerned about their own health or other peoples health | Information Carer support Peer support | Open self referral | Service user chooses, GP referral, referral from other healthcare professionals | 2. Open Access | | |
| Early Diagnosis and support <ul style="list-style-type: none"> for people concerned about their own or other people's memory problems | Memory assessment service Early diagnosis Post Diagnosis Support Continuity of support Involvement of carers and family | Referral including self referral | Service user chooses, GP referral, referral from other healthcare professionals | 3. Early response/ brief intervention (ERBI) | | |

| | | | | | | |
|--|---|-----------------------------|-------------------------|--|--|---|
| <p>Living Well with dementia</p> <ul style="list-style-type: none"> • quality of life for people diagnosed with dementia | <p>Specialist assessment & treatment</p> <ul style="list-style-type: none"> • management of stress & distress <p>Dementia friendly:</p> <ul style="list-style-type: none"> • Intermediate care • Care home care • Housing with telecare • End of life care <p>Personal support/ anticipatory care p Continuity of post diagnostic support Peer support</p> | <p>GP or secondary care</p> | <p>By referral only</p> | <p>4. Longer term multi disciplinary care</p> | | <p>I can enjoy life</p> <p>I am given the right information at the right time and in the right way, so I make good decisions and provide for future decision making</p> |
| <p>Acute illness</p> | <p>Inpatient dementia care:</p> <ul style="list-style-type: none"> • Dementia friendly care in general hosp • Risk management • Physical healthcare | <p>GP or secondary care</p> | | <p>5. Intensive treatment</p> | | <p>I am treated with dignity and respect</p> <p>I get the treatment and support which are best for my dementia, and my life</p> <p>I am confident my end of life care wishes will be respected. I can have a good death</p> |

Appendix 5. Charter of Rights, and Standards of Care for People with Dementia, their family and their Carers in Scotland 2009.

Preamble

In pursuance of Human Rights Act 1998 and The Scotland Act 1998 the rights contained within this charter are based on internationally agreed human rights and are intended to promote the respect, protection and fulfilment of all human rights of people with dementia and their Carer, as guaranteed in the European Convention of Human Rights, the Universal Declaration of Human Rights, the International Covenants on Economic, Social and Cultural Rights and Civil and Political Rights, and the Convention on the Rights of Persons with Disabilities, the key principles of which are:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- Non-discrimination
- Full and effective participation and inclusion in society
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- Equality or opportunity
- Accessibility
- Equality between men and women

The Charter also reflects other legal provisions and in particular the principles of the Adults with Incapacity (Scotland) Act 2000; the Mental Health (Care and Treatment) (Scotland) Act 2003, and the Adult Support and Protection (Scotland) Act 2007.

The Charter is guided by a human rights-based approach (known as the **PANEL** approach, endorsed by the United Nations).

It emphasises the rights of everyone to:

Participate in decision which affects their human rights

Accountability of those responsible for the respect, protection and fulfilment of human rights

Non-discrimination and equality

Empowerment to know their rights and how to claim them

Legality in all decisions through an explicit link with human rights legal standards in all processes and outcome measurement

People with dementia and their Carer, at every stage of the illness and wherever they are, have the following rights

Participation

1. People with dementia and their Carer have the right to be provided with accessible information and the support they require in order to enable them to exercise their right to participate in decisions which affect them
2. People with dementia and their Carer have the right to live as independently as possible with access to recreational, leisure and cultural life in their community
3. People with dementia and their Carer have the right to full participation in care needs assessment, planning, deciding and arranging care, support and treatment, including advanced decision making
4. People with dementia and their Carer have the right to be assisted to participate in the formulation and implementation of policies that affect their well-being and the exercise of their human rights

Accountability

5. People with dementia and their Carer have the right to be able to enjoy human rights and fundamental freedoms in every part of their daily lives and wherever they are, including full respect for their dignity, beliefs, individual circumstances and privacy
6. Public and private bodies, voluntary organisations and individuals responsible for the care and treatment of people with dementia should be held accountable for the respect, protection and fulfilment of their human rights and adequate steps should be adopted to ensure this is the case.

Non-discrimination and equality

7. People with dementia and their Carer have the right to be free from discrimination based on any grounds such as age, disability, gender, race, sexual orientation, religious beliefs, social or other status.

Empowerment

8. People with dementia have the right to access appropriate levels of care providing protection, rehabilitation and encouragement.
9. People with dementia have the right to help to attain and maintain maximum independence, physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life
10. People with dementia and their Carer have the right to access opportunities for community education and lifelong learning
11. People with dementia have the right to access to social and legal services to enhance their autonomy, protection and care

12. People with dementia have the right to health and social care services provided by professionals and staff who have had appropriate training on dementia and human rights to ensure the highest quality of service

Legality

13. People with dementia and their Carer have the right to have the full range of human rights respected, protected and fulfilled. In addition to those explicitly contained in the Human Rights Act 1998, these include:

- the right to live in dignity and security and be free of exploitation, violence and physical, mental or sexual abuse;
- economic, social and cultural rights including the right to an adequate standard of living including social protection; and
- the right to the highest attainable standard of physical and mental health

14. People with dementia and their Carer have the right to information, to participation in decision making and, where rights are not observed, the right to seek remedy through effective complaint and appeal procedures

15. People with dementia have the right, regardless of diagnosis, to the same civil and legal rights as everyone else. Where someone lacks capacity to take a specific action or decision due to their mental disorder, anyone acting for them must have regard for the principles and provisions of the Adults with Incapacity (Scotland) Act 2000. These principles are enshrined in Article 12 of the Convention on the Rights of Persons with Disabilities which sets out international standards in relation to legal capacity. In summary, any intervention on behalf of the person with dementia who lacks capacity must:

- benefit the person
- restrict the person's freedom as little as possible whilst still achieving the desired benefit
- take account of the person's past and present wishes (with appropriate support to assist communication)
- take account of the views of relevant others and
- encourage the person to use their existing abilities and to develop new skills

Reproduced from the Charter of Rights for people with dementia and their carer in Scotland; a full copy is available from the link below:

<http://www.dementiarights.org/charter-of-rights/>

Standards of Care

The standards were developed by the Scottish Government and the Mental Welfare Commission in 2011 to help people with dementia, their families and carers understand their rights, and how these rights can help make sure that they receive the support they need to stay well, safe and listened to.

People with dementia retain the same rights as anyone else in society but the nature of their illness means that they may have difficulty in protecting these rights.

These standards relate to everyone with a diagnosis of dementia in Scotland regardless of where they live, their age, the supports they receive or the severity of their illness. This includes younger people, people with a learning disability and people with rare types of dementia. They apply to people living in their own homes, care homes or hospitals, especially general hospitals.

The two main sources of information which underpins these standards are:

1. The Charter of Rights for People with Dementia and their Carers in Scotland.
2. What people with dementia and their carers in Scotland have identified as being important to them and what they want from services.

The standards should be used in conjunction with Promoting Excellence: A framework for health and social care staff working with people with dementia, their families and carers. The framework outlines in detail the skills and knowledge health and social care staff should have depending on the role they play in supporting people with dementia. Organisations are identified that have the main responsibility to make sure that each standard is met. The standards require organisations to work together and reflect a right's based approach to reduce barriers, stigma and discrimination, improving opportunities for people with dementia to access care, support and treatment.

The Standards framework

- I have the right to a diagnosis
- I have the right to be regarded as a unique individual and to be treated with dignity and respect
- I have the right to access a range of treatment, care and supports
- I have the right to be as independent as possible and be included in
- I have the right to have carers who are well supported and educated about dementia
- I have the right to end of life care that respects my wishes

This section has been reproduced and adapted from the Standards for Care for Dementia in Scotland: Action to support the change programme, Scotland's Dementia Strategy 2011, the full document is available from the following link:

<http://www.scotland.gov.uk/Resource/Doc/350188/0117212.pdf>

References and links

1. Scotland's Dementia Strategy 2010
<http://www.scotland.gov.uk/Publications/2010/09/10151751/0>
2. Charter of Rights for people with dementia and their carers in Scotland 2009
<http://www.dementiarights.org/charter-of-rights/>
3. Standards for Care for Dementia in Scotland: Action to support the change programme, Scotland's Dementia Strategy 2011
<http://www.scotland.gov.uk/Resource/Doc/350188/0117212.pdf>
4. Remember I am still me (2009) Care Commission & Mental Welfare Commission, Edinburgh
[http://library.nhsggc.org.uk/mediaAssets/dementiasp/remember_im_still_me_-_may_09\[1\].pdf](http://library.nhsggc.org.uk/mediaAssets/dementiasp/remember_im_still_me_-_may_09[1].pdf)
5. An estimate of the number of people with dementia in your Scottish local authority area:
<http://www.vhscotland.org.uk/library/vol/dementiastats09.pdf>
6. The number of people on the Quality and Outcomes framework dementia register and other equivalent resources:
<http://www.scotland.gov.uk/About/scotPerforms/partnerstories/NHSScotlandperformance/>
7. NICE Dementia Guideline:
<http://www.nice.org.uk/cg42>
8. Management of patients with Dementia: A National Clinical Guideline
NHS Quality Improvement Scotland:
<http://www.sign.ac.uk/pdf/sign86.pdf>
9. The planning, organisation and delivery of joined up services for those with dementia and their carers, NHS HDL 2004 44
http://library.nhsggc.org.uk/mediaAssets/library/qis_OOH_LRP_ARGC06.pdf
10. NHS Quality Improvement Scotland Integrated Care Pathway Toolkit Dementia:
[http://library.nhsggc.org.uk/mediaAssets/dementiasp/mentalhealth_standardsforICP_DEC07\[1\].pdf](http://library.nhsggc.org.uk/mediaAssets/dementiasp/mentalhealth_standardsforICP_DEC07[1].pdf)
11. Leading For Outcomes: Dementia 2011, Institute for Innovation and Research in Social Services:
<http://www.iriss.org.uk/resources/iriss-leading-outcomes-guide01>
www.iriss.org.uk
12. Dementia Gateway: Getting to know the person with dementia
<http://www.scie.org.uk/publications/windowsofopportunity/journey/index.asp>
13. Alzheimer Society (2007) Dementia UK available at
http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=342

14. The Scottish Dementia Working Group, the independent group of people with dementia, www.sdwg.org.uk
15. Facing dementia: how to live well with your diagnosis, Health Scotland, <http://www.scie.org.uk/publications/windowsofopportunity/personalresources/index.asp>
16. Coping with Dementia: a practical guide for carers, (2009), NHS Health Scotland www.healthscotland.com/documents/1469.aspx
17. Talking Mats help involve people with dementia and their carers in decision-making, Joseph Rowntree Foundation, 2010 : <http://www.jrf.org.uk/publications/talking-mats-decision-making>
18. Crampton, J. Eley, R. [and] Dean, J. (2012). Creating a dementia-friendly York. London: Joseph Rowntree Foundation (JRF), October 2012 <http://www.jrf.org.uk/sites/files/jrf/dementia-communities-york-summary.pdf>
19. Supporting those with dementia: reminiscence therapy and life story work, IRISS Insights, 2010 available at: <http://ix.iriss.org.uk/collections/IRISS%20Insights>
20. Improving communication around outcomes: a resource to support reflection and practice development <http://www.jitscotland.org.uk/action-areas/talking-points-user-and-carer-involvement/communication-skills/>