

Agenda Item	4.
Report No	COG 02/19

## Draft Highland Dementia Strategy 2018 - 2022

### Summary

The CPP COG is asked to consider the attached draft strategy document, specifically the proposed Highland Outcomes. It is asked to provide comment on the draft to date and provide ideas for developing the strategy, and most specifically the actions, further.

### 1. Background

A cross sector, multi-disciplinary group was formed as a sub group of the Adult Strategic Commission Group (ASCG) to take forward a plan for translating the National Dementia Strategy into Highland. <https://www2.gov.scot/Topics/Health/Policy/Dementia>

The group included representatives from carers, users and both the public and third sectors. The group did not include membership from the uniformed services.

The attached plan was the result of our initial work to develop a specific set of Highland outcomes informed by the national strategy. The proposal is to consider how this work can now work to engage a broader group of stakeholders for input and feedback to refine both the outcomes and populate the necessary outcomes for achieving these aspirations.

### 2. The Highland Outcomes

Below are the things that we in Highland have committed to prioritising to make things better for the people of Highland, specifically those who are affected by dementia. A separate priority action is proposed to develop from the next stage of engagement work.

It is important to understand that we know and recognise that those who are affected by dementia include those who live with dementia, their carers, family and friends. To achieve these outcomes we are wholly committed to delivering these outcomes in relation to the needs of all of those who are affected by dementia.

1. People have increased say and control over their dementia diagnosis and are diagnosed early enough that they can take as full a part as possible in their own care planning
2. People get access, at the point they wish for the support, to good quality, person-centred post-diagnostic support in a way that meets their needs and circumstances
3. People with dementia are enabled to live well and safely at home or in a homely setting, with consideration for their whole wellbeing, for as long as they and their family wish
4. The critical input of family and other carers is encouraged and facilitated and

- carers' own needs are recognised and addressed
5. There are more dementia-friendly and dementia-enabled communities, organisations, institutions and initiatives.
  6. People with dementia's right to good quality, dignified, safe and therapeutic treatment, care and support is recognised and facilitated equally in all care settings, (For example, at home, in care homes or in acute or specialist NHS facilities)
  7. People get timely access to good quality palliative and end of life care
  8. People affected by dementia, staff from support services, organisations, community groups and public agencies are well informed and aware of the work being undertaken within Highland under this strategy and are actively involved in service planning and delivery.

### **Recommendations**

The COG are asked to consider the following:

- Are the proposed outcomes a relevant translation of the National Dementia Strategy?
- Are there specific actions or activities which your organisations are already undertaking which should form part of the next stage for action planning?
- Are the COG willing to support the general direction of travel with the Highland strategy?



# **HIGHLAND DEMENTIA STRATEGY**

**2018 - 2022**

## Foreword

This document is a collaboration across sectors and includes the voices of those who have experience of dementia and caring. It takes account of the National Strategy launched in 2017 and considers how we can localise those aspirations outcomes for the people of Highland.

The context of meeting the needs and developing innovation is complex and challenging in our current economic climate. At a time when we arguably need to look at releasing more resources, of all types, into delivery of these ambitious outcomes is precisely the time that all organisations and public agencies are facing financial constraints. We can't, however, allow that to temper our ambitions it is precisely because people who are affected and live with dementia rely on our ability to deliver these outcomes, that we must endeavour to face that challenge with a renewed commitment.

### Highland Dementia Working Group

It is great for us, as people living with dementia in the Highlands, to have our voices heard and we truly value having the opportunity to contribute our thoughts and opinions to the new strategy. As a group, the HDWG strive to make things better, and improve the lives of people and families living with dementia in the Highlands.

We believe that 'no one size fits all'; dementia care needs to be person-centred, flexible and tailored to the individual. A holistic approach is vital and many of the commitments within this strategy reflect this. To meet that need we need to ensure true collaboration across all services and sectors.

At the HDWG we advocate dementia friendly community initiatives and feel there is great strength in educating the wider society on dementia. We champion the on-going need for good quality post-diagnostic support, early diagnosis and personalised, meaningful support for people throughout their journey with dementia.

### Connecting Carers

Role of Carers

### Adult Strategic Commissioning Group (ASCG)

The Adult Strategic Commissioning Group welcomes the development of a Highland Dementia Strategy and we thank all those who have taken part in its development.

As a group we look forward to working with the strategy and informing our commissioning processes to align resources and commitments to the delivery of the outcomes and impacts that the document commits all of us to.

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## Our Vision

In Highland we share the vision articulated nationally which sees people affected by dementia able to access timely, skilled and well-coordinated support from diagnosis to end of life. That though our methods of delivery and achieving outcomes are tailored to the needs and community of those affected by dementia achieving the outcome will always be possible.

## Developing The Highland Strategy

A short life working group met in January 2018 to progress drafting an initial Highland Dementia Strategy on behalf of the Adult Strategic Commissioning Group (ASCG). Membership to the group included a wide range of experience and interest across clinical, strategic, Board and public health within NHS; Highland Council, Third Sector and carers.

In April 2018 the group presented the draft strategy, outlining the proposed Highland outcomes, based significantly around the National Outcomes, and some recommendations for development of an action and implementation plan to the ASCG to consider and approve.....

## National Context

The legislative framework for the integration of health and social care services is provided by the [Public Bodies \(Joint Working\) \(Scotland\) Act 2014](#). In Highland we have a lead agency model with NHS Highland providing health and social care for adults. The integration of services provide new opportunities for innovation and design of services for people living with dementia.

Additionally the following legislation also supports people with dementia and their carers, including:

- The [Carers \(Scotland\) Act \(2016\)](#) sets out the entitlement of carers to assessment and care planning, with support options for people who meet eligibility criteria.
- The [Social Work \(Self Directed Support\) Scotland Act \(2013\)](#) confers upon people with assessed social care needs the right to exercise choice and control over how their care package is put together.
- The [Adults with Incapacity \(Scotland\) Act 2000](#) safeguards the interests of persons who lack capacity to make some or all decisions for themselves. It enables carers or others to have legal powers to make welfare, health care and financial decisions on their behalf.

Since 2007, dementia has been identified by the Scottish Government as a national priority. The new three year [National Dementia Strategy \(2017-20\)](#), sets out a number of commitments around post diagnostic support, coordinated service delivery, a strong focus on integrated working, improvements to palliative and end of life care, and a renewed focus on improving the care and support provided to people with dementia in group settings such as care homes and hospitals. The [Standards of Care for Dementia](#) describe the range of rights people with dementia and their carers have, and provides guidance to care providers in the standards to be met by all professionals involved in the care of people with dementia.

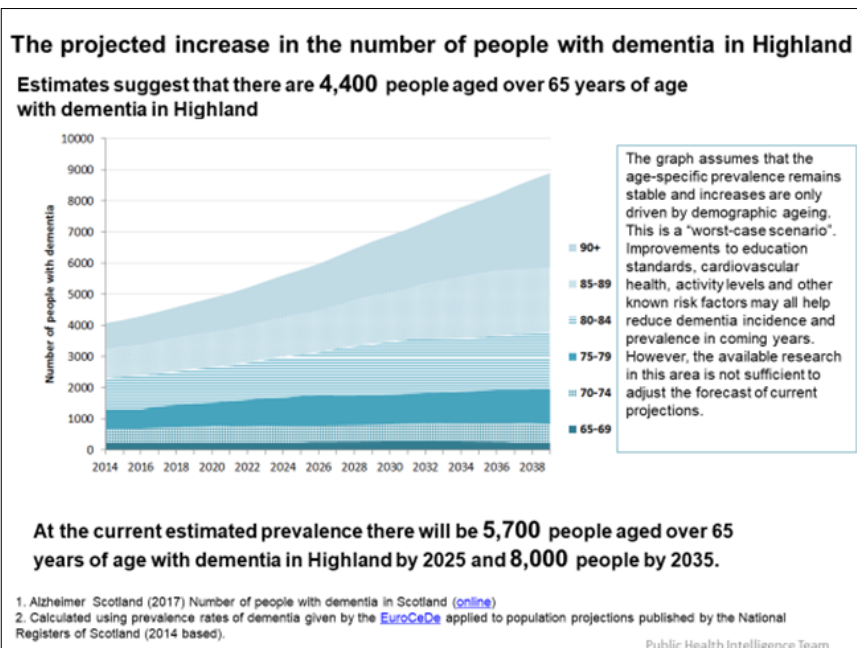
These are:

- 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 to be included in my community
- I have the right to have carers who are well supported and educated about dementia
- I have the right to end of life care that respects my wishes.

## Highland Context

The number of people in Scotland with dementia stands at around 90,000 and is expected to double within 20 years, partly due to an increase in our aging population, improved techniques in identifying and diagnosing dementia earlier than before, and lifestyle factors. Age is the most important risk factor however and it is estimated that the risk of dementia doubles every additional five years after the age of 30, although this starts at a very low level (Stark and Connelly 2013). In Highland approximately 21% of our population is aged over 65 years.

We estimated 4,400 people are living with dementia in Highland but we, acknowledged there are potentially many more who have not sought or received a diagnosis. By 2035 it's predicted the number of people with dementia in Highland will almost double and be an estimated 8000. Each year in the Highlands around ..... people receive a new diagnosis of dementia. Currently 1 in every 12 people in Highland is living with dementia increasing to 1 in 9 people by 2035. (fig 1) Dementia and Alzheimer's Disease now account for more than one in every ten deaths in Scotland (NRS, 2018)



Services must begin to adapt now in response to the increasing number of people with dementia and the shifting culture of care towards home and the community. We must also consider that dementia results in a spectrum of care needs, coexisting illness and challenging behaviour can also pose special problems in care and supervision. Currently the burden of care falls on informal caregivers and residential and nursing homes (Stark and Connelly 2013).

The current cost of health, social care and accommodation for people living in Highland with dementia is an estimated £..... million per year; by 2035 this will have increased to over £..... million per year.

Carers and people with dementia themselves are the experts in caring for and understanding the individual needs and preferences and must continue to play a vital role in ensuring a good quality of life

and be supported well to do so. It has been estimated that the care and support carers provide is worth over £..... million per year in Highland.

National policy focuses on a range of issues including improving diagnosis rates and the provision of post-diagnostic support, and ensuring the highest quality of care and support for people with dementia at every stage of the illness as well as continuing the work with dementia friendly communities. The 3rd Dementia Strategy for the first time addresses issues in dementia practice all the way from pre-diagnosis to palliative and end of life care.

Much of this work is already underway in Highland however a strategic approach is needed to ensure the gap between policy and practice is narrowed and there is equity of outcome for all individuals in every community; hospital or general practice, home or care home, urban or rural.

This new Highland strategy provides an opportunity for everyone to consider how they can play their part in ensuring that the Highlands is a great place to live for people living with dementia. Large organisations, small community-based services, communities, shops, businesses, neighbours or friends, they all have a role to play.

With 1 in 3 people expected to be affected by dementia as well as a rapidly increasing older population, these figures are set to rise dramatically over the next 10 years. To add to the mix, Highland is a geographically challenging land mass with urban neighbourhoods (where 1 in 5 people are over the age of 65) and rural communities (with 1 in 3 over the age of 65) learning from each's different approaches to dementia care.

NHS Highland's stance on dementia being a long-term illness rather than a specific mental condition has not only helped break down stigma around dementia, but also sanctioned better conversations around dementia care in general. There is a specific dementia focus in hospital wards - including a 'Beacon Ward of Excellence' Award – and examples include Raigmore Hospital supporting carers of people admitted into hospital by means of discreet identification/discounted meals and Lawson Community Hospital providing a dementia trolley with music, art and creative activities for dementia patients. Community Mental Health Team liaison services routinely provide support to people affected by dementia and to hospital staff and VC links are also available to consultant psychologists and memory nurses. All UHI nurses (since 2014) qualify at an enhanced level of dementia, some 50 Dementia Champions work across the Board area and in general the stability and quality of the dementia workforce has improved. Dementia gardens are the norm and dementia specific design is routinely considered during any redesign of building and services.

In the primary sector, more positive experiences are had with GPs who in essence are the gate keepers to early diagnosis and support and together with more flexible post diagnostic one year time frames for Link Workers, more people across Highland have an increased say and control over their dementia diagnosis. There is also now more timely access to good quality palliative and end of life care. Social prescribing is a new trend with primary care working more closely with community services resulting in better engagement and involvement of people with dementia and carers.

Alzheimer Scotland provide an extensive range of innovative and personalised support services in Highland, including a 24 hour dementia helpline and registered therapeutic day support services in Tain, Dingwall, Skye, Inverness and Nairn. They have Dementia Resource Centres in Tain, Dingwall and Inverness with Dementia Advisors covering North and South Highland. Alzheimer Scotland also play a key



role in campaigning for the rights of families affected by dementia as well as providing a wide range of community groups, dementia cafes, supper clubs, carer support groups and education courses for carers, people with dementia and other groups while also supporting dementia friendly community work, including Dementia Friends' information sessions.

In 2015 East Sutherland was a Scottish Government's 2nd Dementia Strategy rural test site with the result that within the Promoting Excellence framework, all NHS health practitioners are now designated specific dementia educational levels, the 8 pillar principles are being imbedded into best practice with local data intelligence supporting better service planning allowing people to come into community mental health services earlier for diagnosis and post-diagnostic support.

The concept of grassroots dementia friendly communities has generated a shift towards community/ neighbourhood solutions e.g. the Boleskin and Black Isle Carer programmes supported by NHS, Highland Council and Alzheimer Scotland. The Life Changes Trust has also been a force for transformational change across Highland by funding projects like Paths for All, Care and Repair enablement, housing adaptations, various empowerment projects as well as a number of rural dementia friendly communities including the Helmsdale model which is rolling out across Highland via the Community Planning Partnerships.

Various forms of social interactions for people affected by dementia are available with music, art, dance and creative activities flourishing across Highlands. While transport, particularly in rural areas though not exclusively, continues to be a problem. Many communities have acquired their own busses and transport people to these activities and medical appointments. Outlets specifically for men are also growing e.g. Evanton Community Woods in partnership with Alzheimer Scotland, NHS Highland, Paths for All and the Forestry Commission encourage those with early onset dementia outdoors into woodlands with regular activities around woodworking, art, cooking and walking.

Carers generally have good access to information and peer support, with both befriending and respite for carers available. Organisations like Connecting Carers ensure that during the process of diagnosis and through all parts of the care journey, the critical input of family carers is encouraged and facilitated with carers' own needs recognised and addressed. Interaction with paid carers to support families affected by dementia is more challenging - particularly in rural areas - because of time pressures, inadequate allowance for travel time and indeed lack of trained personnel. This is changing in places however with self-directed support which is a tailored service for the individual and/or carer to choose the services they require.

Huge strides have been made around aids and adaptations resulting in less time spent in hospitals and a decreased risk of falls. Telehealth supports dementia families across Highland and carers regard systems such as Health Call as invaluable support. Technology has also extended to GPS tracking systems - allowing people with dementia freedom to roam and Police Services to locate people with dementia in emergency situations. While rural interactive screen programmes are encouraging interaction between rural villages to overcome loneliness and isolation.

Finally, as more people with dementia are being diagnosed earlier, so more can take as full a part as possible in their own care planning resulting in earlier access to good quality, person-centred post-diagnostic support in a way that meets their and their carer's needs and circumstances. It also means more people with dementia are enabled to live well and safely at home or in a homely setting for as long

as they and their family wish. We must also consider supporting people to reach the end of their life in the place they wish to die, as far as is possible.

Although we collectively acknowledge and welcome the wealth of work already being done in Highland we see the development of our first Highland Strategy as an opportunity to reinforce a commitment to firstly ensure that resourcing continues to support the development of these services; both to sustain the necessary diversity but also to ensure that delivery can grow to meet the anticipated increase in demand. We need too to better support the needs and resilience of unpaid carers, without whom there is no foreseeable way to sustain our ambitions for care and support for those living with dementia. Finally we need to work with communities to better deliver and develop community based pathways for achieving personal outcomes for those affected by Dementia.

## **The Highland Commissioning and Integration Model**

Within Highland we have a 'Lead Agency Model' of delivering for Health and Social Care. This means that there is a 'wholesale transfer' of services and operational responsibilities in Highland for the delivery of an integrated health and social care service for adults to NHS Highland . Highland Council provide an integrated service for health and social care for children. This is different to elsewhere in Scotland where joint responsibilities across Local Authorities and NHS Health Boards have been placed into new 'Integrated Joint Boards' or IJBs who then take responsibility for the delivery of services across both health and social care.

The Adult Strategic Commissioning Group (ASCG) is the strategic commissioning group for adult services within Highland and will retain primary ownership of this plan and its outcomes. In recognition however, of the need to strengthen a collective ownership and understanding of the vision articulated here active consultation with other public sector partnerships has been part of the formation of our action planning process.

At a local level Community Partnerships who, in addition to other duties, have a responsibility for the development of a localised plan for adult health and social care will be asked to consider the delivery of these outcomes within the local context.

## Our Highland Outcomes

Below are the things that we in Highland have committed to prioritising to make things better for the people of Highland, specifically those who are affected by dementia. A separate priority action plan is overleaf and outlines areas of action that will contribute to these outcomes as directed by our stakeholders and within the context of our collective resources.

It is important to understand that we know and recognise that those who are affected by dementia include those who live with dementia, their carers, family and friends. To achieve these outcomes we are wholly committed to delivering these outcomes in relation to the needs of all of those who are affected by dementia.

1. People have increased say and control over their dementia diagnosis and are diagnosed early enough that they can take as full a part as possible in their own care planning
2. People get access, at the point they wish for the support, to good quality, person-centred post diagnostic support in a way that meets their needs and circumstances
3. People with dementia are enabled to live well and safely at home or in a homely setting, with consideration for their whole wellbeing, for as long as they and their family wish
4. The critical input of family and other carers is encouraged and facilitated and carers' own needs are recognised and addressed
5. There are more dementia-friendly and dementia-enabled communities, organisations, institutions and initiatives.
6. People with dementia's right to good quality, dignified, safe and therapeutic treatment, care and support is recognised and facilitated equally in all care settings, (For example, at home, in care homes or in acute or specialist NHS facilities)
7. People get timely access to good quality palliative and end of life care
8. People affected by dementia, staff from support services, organisations, community groups and public agencies are well informed and aware of the work being undertaken within Highland under this strategy and are actively involved in service planning and delivery.

## **Appendix I: *Our Pan-Highland Commitments***

The following appendix outline activities and commitments that the strategy document identifies as necessary to underpin the deliver of our outcomes. A 'live' action plan which encompasses these commitments and other work as it develops will both describe and drive the work across Highland around delivery of our outcomes.

That plan will belong to the Dementia Working Group, who will be responsible for ensuring that our commitments are managed and delivered as far as is possible at each stage of development. They will report progress on an annual basis to our stakeholders; people affected by dementia, practitioners and support workers, public agencies and the Third Sector.

To further develop the delivery of our regional work we will also support the development of local dementia action plans in the Caithness, Sutherland, East Ross, Mid Ross, Skye Lochalsh and Wester Ross, Lochaber, Inverness, Nairn and Badenoch and Strathspey areas. The local plans will inform and be informed by the regional action plan.

## Delivering Our Outcomes:

**Outcome: People have increased say and control over their dementia diagnosis and are diagnosed early enough that they can take as full a part as possible in their own care**

What we will do	How we will do it	How we will know if it worked

**Outcome: People get access, at the point they wish for the support, to good quality, person-centred post diagnostic support in a way that meets their needs and circumstances**

What we will do	How we will do it	How we will know if it worked

## Delivering Our Outcomes:

**Outcome: People with dementia are enabled to live well and safely at home or in a homely setting, with consideration for their whole wellbeing, for as long as they and their family wish**

What we will do	How we will do it	How we will know if it worked

**Outcome: The critical input of family and other carers is encouraged and facilitated and carers' own needs are recognised and addressed**

What we will do	How we will do it	How we will know if it worked

## Delivering Our Outcomes:

**Outcome: There are more dementia-friendly and dementia-enabled communities, organisations, institutions and initiatives.**

What we will do	How we will do it	How we will know if it worked

**Outcome: People with dementia's right to good quality, dignified, safe and therapeutic treatment, care and support is recognised and facilitated equally in all care settings, (For example, at home, in care homes or in acute or specialist NHS facilities)**

What we will do	How we will do it	How we will know if it worked

## Delivering Our Outcomes:

### Outcome: People get timely access to good quality palliative and end of life care

What we will do	How we will do it	How we will know if it worked

### Outcome: People affected by dementia, staff from support services, organisations, community groups and public agencies are well informed and aware of the work being undertaken within Highland under this strategy and are actively involved in service

What we will do	How we will do it	How we will know if it worked



## **Contributors To The Plan:**

Alzheimer's Scotland

Connecting Carers

Dementia Friendly Communities

Highland Senior Citizens Network

Highland Council

Highland Home Carers

Highland Third Sector Interface

NHS Highland

Public Health

