Response to a "Deep Dive" Assessment of Dementia Services for NHS Shetland and Shetland Islands Council.

In September 2013 a "deep dive" assessment of key strategic and service provision issues relating to dementia services in Shetland was undertaken by Professor June Andrews of the Dementia Services Development Centre (DSDC) based at the University of Stirling in partnership with Mark Butler, Director of Development (DSDC) and Director of the People Organisation.

The "deep dive" approach was designed to look at both strategic and practical issues. The visit was conducted intensively with face to face meetings in Shetland over a period of three days. Part of the approach was to follow the direct experience of people with dementia and their carers through services and pathways from pre-diagnosis onwards. The methodology involved direct engagement with staff at all key points on the pathway. This allowed important potential changes to be worked through with front-line staff at the time of the visit.

This paper is the first step in an island-wide engagement process that aims to develop Shetland as a "dementia friendly" community. It is intended that an initial small short-life working group, consisting of appropriate stakeholders, will be convened to develop an action plan, before presenting the plans more widely. It is intended that this group will consist of representatives from statutory and third sector partners, including clinicians and practitioners, as well as people with dementia and carers. This group will also drive the development of the local Dementia Strategy.

The following sections summarises the findings of the Deep Dive assessment, with their recommendations, as headings in a table to form the basis of an action plan, which will be developed to address these.

Findings

Diagnosis of dementia

Diagnosis rates in Shetland were found to be good and the Specialist Dementia Diagnostic service was highlighted as "working in an exemplary way". However there appeared to be several different pathways to diagnosis. Although, each had their place, there were concerns about differences of opinion amongst some professionals regarding how the diagnosis was reached and recorded.

The pathway following diagnosis was not clear and there was lack of clarity over key worker responsibilities for the "whole journey" from diagnosis to end of life.

Family support

Alzheimer Scotland was valued for providing support.

It was identified that people with dementia and their carers wish to be supported to remain in their own homes. However information about what is available to support this was absent.

In addition more training and an awareness of the resources and options for GPs and primary care workers is required.

There was a need to promote services and approaches that support independent living.

Acute episodes of disturbing behaviour

It was identified that there was a lack of confidence expressed by staff in the prevention of disturbing behaviour and their ability to manage it when it arose.

The designated "place of safety" beds in the Gilbert Bain hospital were deemed unsuitable due to their "design, location and staffing".

An appropriate way of managing people presenting with disturbing behaviour needs to be identified on-island.

Care Centres

Care centres need to be seen as an end-of-life facility, with "short lengths of stay and direct admission from the community" rather than the "long-term and appropriate response" for people with dementia.

There needs to be a better balance of care centre beds and supported accommodation to allow more people to remain independent in a homely environment.

Viewforth was not seen as a "dementia specialist" unit and any re-provisioning of it should be done in the context of overall planning of resources for people with dementia. Other care centres were found to have a high proportion of residents who had dementia who were being managed in a more appropriate environment than Viewforth and this should be taken into account in any review.

The importance of involving housing representatives needs to be highlighted in future discussions.

Staffing

There were concerns about levels of knowledge about dementia found across a range of disciplines. There need to be systems in place to ensure that CPD relating to dementia is appropriate and tracked for all staff.

By increasing knowledge of dementia and confidence in management of it by those currently seen as non-specialists, it is more likely that people with dementia will be able to remain in an appropriate environment rather than requiring the involvement of specialist staff.

Issues were identified relating to clarity of roles and responsibilities as well as governance of services for people with dementia.

Concerns about future employment of staff in Viewforth may be having an adverse effect on the care provided.

There was lack of clarity of pathways in and out of Ronas ward for people with dementia.

Complaints and public impressions

There was the impression that there was a lack of support for staff from "councillors, other politicians and senior managers".

A joint complaints procedure is set out in the CHCP Agreement but there is clearly a need to make this procedure better understood and there is a need to review how this procedure works in practice.

The local media should be used to report on positive examples of care within statutory services. It was found that there was a perception that local media highlighted the positive work of the voluntary sector and focussed on complaints about statutory services, giving a biased view.

Education

There is a need to review the effectiveness of the Dementia Champion programme facilitated by NHS Education Service Scotland (NES) in light of feedback from some staff who have completed it.

It was identified that staff who were trained to deliver validated training to colleagues have not rolled out training as expected.

It is not clear who has had training in dementia and to what level.

Leadership

There is insufficient strategic leadership for the management of people with dementia in either health or social care systems. It should be seen as a separate component for service planning and development. It is recognised separately in the CHCP Agreement and in the past there was separate strategy development and redesign programmes focussed on dementia. The action here needs to be reinvigorated.

There is lack of clarity over future priorities with regards to planning and delivery of appropriate care. There seems to be a reluctance to engage with the public and there was evidence of differing

views which resulted in “planning processes for important elements of island provision of services stalling”.

There is a need for effective leadership by senior executives in managing “staff processes, the political influence and the media fall out”.

Risk

Lack of confidence of staff resulted in an increased perception of risk.

Public perception of dementia was flawed resulting in a perception that people with dementia needed to be looked after in a secure setting.

There appears to be a disproportionate emphasis on the management of risk in a small number of people who presented with disturbing behaviour resulting in reluctance for positive risk taking in general.

It was felt that any review of dementia services should be done independent of the Mental Health review to enable it to be seen as a “broader public vision for community development”.

The Dementia Services Partnership (DSP), though seen as a “sound idea” required more clarity with regards to their responsibilities and accountabilities. Criticism was made that social work appears to be excluded from the DSP, though this was not the case as a request has been made for representation, which has not yet happened.

Future proofing

There seem to be issues with the current planning processes that prevents investment in better dementia care and support from being implemented. Much of what needs to be done requires a shift in established culture and thinking to provide future care in a different way. Properly addressed this has the potential to be economically better for Shetland.

Proposed Action Plan

Recommendation from Deep Dive	Where we are	Where we want to be	What we need to do	When and who
Develop a Dementia Friendly Vision	Activities that include people with dementia in their communities, e.g. activities	To establish Shetland as a place where people with dementia and their carers are	A public engagement process should be initiated involving diverse stakeholders	

	organised by Alzheimer Scotland. Inclusion of people with dementia and carers in planning activities and events. Events during Dementia Awareness week. Involvement with local media has begun to raise dementia awareness and importance of early diagnosis. Training for staff in Mareel and Bigton Community Shop. Use of nationally agreed signage being rolled out in NHS premises. Environmental audits carried out in GBH. Dementia friendly housing solutions created in King Eric House.	able to participate as fully in that community as possible without feeling discriminated against.	including people with dementia, carers, bus operators, taxi firms, police, fire and rescue services, shopkeepers, NHS Shetland, SIC, charities, care providers, faith groups and schools.	
Mapping	Process mapping was carried out as part of an overall Mental Health referral	To understand fully how people with dementia and carers access services, what there is and how	An externally facilitated exercise should be commissioned that will involve	Health Improvement Scotland will be approached to facilitate. April 2014.

	process and this was used as a basis for development of the referral pathway for the Dementia Assessment Service. A mapping exercise was carried out to try and map the pathway in the GBH.	these services operate. This will allow greater clarity of how resources can be better used to improve care of people with dementia and their carers.	"professionals of all disciplines and the public in mapping current models of care, resources, locations, staffing, processes and protocols"	
Leadership	There is some leadership in place at Operational levels.	A vision for Shetland as a dementia friendly community should be developed with the responsibility to lead on this clear. This leadership must be established from current senior staff; elected, non-executive and executive positions who have responsibility and authority to act as visible change agents.	As part of the integration agenda, decisions should be made about who will lead on developing a Dementia Friendly Community. This should be at a high level and be someone who can take into account all aspects of future planning of services in Shetland. It should be identified and agreed as to where the expertise in the field of dementia lies and account taken of this across organisational and departmental boundaries.	

			Development of a local Dementia Strategy based on the current National Dementia Strategy should be a priority.	
Resources	Through the development of the DSP, we have created a group of key individuals involved in providing services to people with dementia and carers.	Resources, financial and human that are required to meet dementia needs must be clarified and based on best practice.	A reappraisal of current resources should be carried out transparently involving public and professionals. If a zero-base budget approach to funding is adopted it will identify where resources are currently deployed and allow how they may be better used.	
Capacity Development	As part of the re-provisioning of Viewforth, some staff have been redeployed into community roles. The post of Alzheimer Scotland Dementia Clinical Nurse Specialist has been created through short-term funding from Alzheimer Scotland. Alzheimer	A model of care will be implemented that is person centred and designed to ensure that people with dementia are able to live as independently as possible, regardless of where in Shetland they live. All staff supporting someone with dementia will be equipped with	As a result of a resources review, it is likely that new roles can be developed to reinforce different models of care. There will need to be a commitment to training and development of people to fulfil these roles. A skills and assets audit should be carried out to identify current and future	

	Scotland has created the posts of Dementia Advisor and Activities Co-ordinator.	the necessary skills to allow this model to be followed.	requirements. A “single hub for training and knowledge development in dementia care” should be created to ensure that professional staff in all areas are trained to the same levels of knowledge and practice.	
Innovation	Current model of Dementia Assessment Service. Redesign of housing to meet the needs of people with dementia, (e.g. Bruce Hall in Unst, King Eric House, Annsbrae).	Create a positive image of innovative care and practice within Shetland to challenge some of the negative views that are evident.	An event should be organised to showcase the developments in dementia care locally, that also involves professionals and the public in determining future ideas for developing. Involve the media locally to report on the positive changes that have happened and are going to happen, including positive experiences of off-island treatment as well as on-island. Further develop housing stock to be dementia friendly by establishing funding sources	

			locally to support this. Share current innovative practice outside Shetland and seek funding for further innovation through application to charitable sources such as Life Changes and the Big Lottery.	
Services	Support and advice is available locally and from NHS Grampian with respect to people presenting with disturbing behaviour. Dementia Services Partnership, DSP, is in place that brings together workers from health, social care and voluntary sector to discuss and provide care for people with a	There needs to be a resource on-island to support people presenting with disturbing behaviour who need short-term time out from the environment that is likely to be causing the behaviour. The DSP needs to further develop in order that it is more visible, with clear pathways, responsibilities and accountabilities. Representation by a named Social Worker should be	Develop a small unit that can be made operational at short notice when required. This would be staffed by specially trained staff who would work in other roles when not required. The draft Standard Operational Procedures for the DSP need to be approved. The Partnership needs to be publicised widely. A Social Worker should be identified who has experience and responsibilities for dementia care and who will attend meetings regularly.	

	diagnosis of dementia and their carers. This meets fortnightly on Thursday mornings at Annsbrae. Draft Standard Operational Procedures have been developed.	established.	Review joint procedure in the CHCP Agreement. Develop a more detailed process.	
Directory	An initial list of local and national services has been developed.	There needs to be easily accessible information about dementia, what services are available and how to access them. This should be available in formats that can be accessed by all, including online and hard copies.	Develop a stand alone website including a Service Directory, clear information about dementia pathways as well as information on dementia. Develop and publish a Service Directory.	

Conclusion.

This "Deep Dive" assessment has been helpful in providing a snapshot of views obtained from external experts over a short space of time and has highlighted a range of issues that require addressing. The outline Action Plan above will be developed to address all of these issues over an agreed timeframe.

From further discussions it has been agreed that there are three main priorities that should be focussed on as a matter of priority;

The importance of an accurate diagnosis and treatment where required.

The general perception needs to be changed to reflect the advantages of this and the range of options available to support the person and family following diagnosis. The lack of accurate knowledge available and a tendency to deploy avoidance techniques to minimise the extent of memory problems, results in people who may have dementia not going to their doctor for help.
It is important that all people being assessed as possibly having dementia are done so using an agreed protocol and are offered access to post diagnostic support in a uniform way

regardless of where the assessment is carried out. An agreed assessment pathway will address this.

Develop a Dementia Friendly Community.

Work in this area needs to start with a public awareness campaign which will also address the previous point regarding diagnosis. There are many myths around regarding dementia which need dispelled. Addressing issues such as why the person's own home should be the preferred option for a person with dementia rather than long-term care in a Care Centre being one example. The outcome should be to create an island where people with dementia can access mainstream services that are designed to meet their needs in such a way that they are able to remain connected in their community for as long as possible.

Provide appropriate on-island facilities and access to off-island care.

Whilst acknowledging that whenever possible a person with dementia should remain in their own home, there will be times where this may not be possible. This should only be for short periods due to episodes of disturbing behaviour, the need for specialist hospital treatment or end of life care.

Hospital admission is not usually required for episodes of disturbing behaviour that is often a result of environmental and/or carer stressors that can usually be resolved fairly quickly with the right approach. There is a need to continue to use the services of Royal Cornhill Hospital in Aberdeen, whenever local specialists agree that it is appropriate, however a local resource needs to be developed for the short-term management of disturbing behaviour.

While there has been some criticism of some people with dementia having to be transferred to hospital in Aberdeen, this has been balanced by other very positive experiences of hospital admission, where specialist continuing assessment and treatment has resulted in improvements in their condition. There is a need to highlight this wider as these cases do not receive the attention in the way that negative experiences do.

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