

## University of Stirling Dementia Services Development Centre

### “Deep Dive” Assessment of Dementia Services for NHS Shetland and Shetland Islands Council

#### 1 Introduction

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.

This report for NHS Shetland and Shetland Islands Council is designed to focus directly on two main areas:

- Summary Findings (Section 2) and
- Recommendations (Section 3)

Information on Background and Context, and Methodology, Timing and Process are included as annexes.

#### 2 Summary findings

The summary of findings is set out according to 10 clinical, social and managerial themes. These are designed to provide a clear and direct assessment. More supporting information is available on request.

##### 2.1 Diagnosis

- the diagnosis levels in Shetland are good (that is a high percentage of the expected dementia population has had a confirmed diagnosis), even though we observed a cultural tendency, particularly among medical staff, to express resentment at the political and management processes that gave rise to the push for improved diagnosis
- the possible pathways for diagnosis include the specialist dementia diagnosis service, diagnosis by hospital consultant at Gilbert Bain, and diagnosis by the GP. Each of these has their proper place. There were worrying examples of clinicians questioning each other’s processes, and how the diagnosis was reached and properly recorded
- the pathway for a person with dementia once diagnosed is not well defined. Staff seemed not to understand or value each other’s role or the role of other agencies. The absence of a well-developed approach to key workers for either the whole journey, or for some parts of the journey until end of life, allows too much room for misunderstanding. The resulting multiplicity of “hand offs” is confusing to people with dementia and their carers. It also represents a potential clinical and managerial risk. The creation of a post diagnostic support worker for one year for newly diagnosed people which is being considered will not solve this problem.

- the diagnostic process involving a videoconference with the psychiatrist of old age, who is remote to the islands, appears to be working in an exemplary way. This is an internationally significant development that should be maintained and an idea that could be spread to urban as well as other remote and rural services

## 2.2 Family support

- families appear to appreciate the support that is given by Alzheimer Scotland, though they still have knowledge gaps that should be more systematically filled
- the role of GPs in supporting families could be strengthened by increasing their knowledge, and those of primary care teams, of practical interventions that make a difference to the lives of people with dementia living independently. The importance of equipping primary care teams with confidence and knowledge in this way is also a major contributor to reducing avoidable statutory costs associated with institutionalisation.
- the absence of an easy-accessible and up-to-date directory or map of services means that families (and care professionals) are not clear about what they can reasonably expect from services. This means that they are unaware of some of the new or innovative approaches available and gives rise to an understandable sense that they need to fight for services and improvements.
- the current failure to promote services and approaches which support independent living in a compelling way reinforces a widespread default expectation in the community that institutional care offers the best route post diagnosis and reduces engagement with their own role in support.

## 2.3 Acute episodes of disturbing behaviour

- some elements of the services are over-sensitised to disturbing behaviour and anxious about their management of it when it occurs. This may arise from the handling of historical incidents, the association of dementia with potential aggressive behaviour, the lack of clarity over roles and accountabilities and their “politicisation” of coverage of incidents in the media, but whatever its cause action now needs to be taken to increase confidence and expertise in staff
- the “place of safety” beds in the acute hospital seem unable to function due to their design, location and staffing. (This lies outside the specific remit for the deep Dive but clearly is relevant to it)
- provision of a comprehensive service within the bounds of Shetland (meaning local people do not have to go “off the island”), is clearly important to reduce additional trauma for families and for the small number of people with dementia who exhibit serious disturbing behaviour. A response built around well-trained staff and tele-links should make this an achievable objective.

## 2.4 Care Centres

- the understandable and not untypical expression of public concern about loss of physical facilities and changing models of care should not stand in the way of the bold vision Shetland requires if it is to meet present and future need. Political agreement on core provision of care needs to be resolved as a priority to give public confidence in new ways of working.

- Shetland must address the inherited view about care homes as a safe and natural, long-term and appropriate response rather than end-of-life dementia facilities with short lengths of stay and direct admission from the community
- the balance between care centre beds and care at home or in supported housing needs to be improved
- the popular designation of Viewforth as a “dementia specialist” centre is not supported by the composition of the staff, the design of the building, or the quality of the systems
- the future re-provision of Viewforth’s services is a local matter but our view is that there is a danger that capital money may be spent inappropriately on an out-of-date model. The local community planning processes have proven cumbersome and unhelpfully slow in arriving at a credible future plan based on an integrated model for dementia provision.
- Viewforth and all other care provision and services need to be viewed and planned together in the context of a wider definition of service which includes community capacity and dynamic management of dementia between agencies, families and communities. A move away from having a misleadingly labelled dementia “specialist centre” would be positive.
- the general designation of other care centres as “non dementia” is belied by the composition of the staff, the often good design of the building, and the quality of the systems – and the fact that most residents have dementia.
- the role of housing and the importance of nurturing the right housing stock (and seeing people’s own homes as arena for change) is surprisingly absent from discussion

## 2.5 Staffing

- we have some concerns about the quality of processes that staff from a range of disciplines use to measure their own dementia related knowledge. CPD is an increasing challenge, but the quality, value and impact of dementia-specific needs to be tracked systematically for all staff, including senior medical staff for whom dementia is one component of an ever increasing range of sub-specialisms about which feel they have to remain in command
- while recognising the enormous challenges of confidentiality and appropriate sharing of intelligence, we did note a tendency in staff to communicate informally about people and cases including those in which they were not directly involved and we noted in particular exaggeration about the severity of incidents (and this “inflation” is reflected in a way that is related, if not consequential in the responses of families and elected representatives)
- the need for multiple on-call rotas is a measure of island life, but a reduction in that need in respect of dementia would be assisted by a plan to increase dementia confidence in more staff and reduction in unnecessary risk of dependence on the resilience of key individuals
- there is a risk of individuals and teams being overwhelmed by negativity caused by organisational boundaries and politics - for example joint appointments still seem to be working in “two halves”, for example coping with “gaming” behaviours and resentments over budget cuts and protection

- staff in Viewforth are notably anxious about their employment and this anxiety is affecting families and possibly residents
- some of the key people in making dementia services work in Shetland feel there are limits to their roles and responsibilities and this leads to a governance issue over ownership of action and behaviours – for example some who feel they are in purely advisory roles are thought by others to be responsible for care and related issues and vice versa. The significance of this is that people with dementia may fall between two stools.
- half the patients on Ronas ward at any time have dementia but there does not appear to be a clear understanding of the community services from which they have come or to whom they will be passed

## 2.6 Complaints and public impressions

- councillors, other politicians and senior managers were reported as not being supportive enough of staff in their public statements and actions, and the history of suspensions and movement of staff and delays in replacing them has affected morale
- there was a great emphasis on complaints and criticism of handling of one complaint during the period of interaction with Shetland services
- there is no joint Shetland vexatious complaints handling policy, and this will give rise to difficulties until this is resolved
- the local pattern of escalation of complaints to include the involvement of elected representatives makes political communication by the health care system even more important here than in any other community
- the local media is not used sufficiently to extol the virtues of the statutory services but covers complaints issues, giving a biased impression that the voluntary sector is the “champion” of people with dementia “against” the statutory services. This must be more actively addressed.

## 2.7 Education

- staff unhelpfully confuse the “dementia awareness” experiences that they have had with “dementia education” which is required to equip them with the knowledge of the practical interventions and responses which build their confidence and increase the quality and impact of what they do
- a considerable investment in time and travel is continuing to be made in sending staff to take part in the Dementia Champions programme arranged by NES, without attending to the feedback that it did not have enough practical value for them
- of the fifteen health and social care staff who were trained as facilitators for the DSDC best practice programme in 2010, with a grant from DSDC, only four were supported at work to go on to undertake the required workplace training of a small group of colleagues. One has excelled by training sixteen colleagues and having other colleagues in the pipeline. Eleven selected staff therefore have materials for training up to 88 colleagues between them in Shetland but have done nothing with their materials or the training they received. We raise this as a management issue.
- in the absence of clarity on working arrangements and responsibilities across boundaries any attempt to assess what skills are needed where, and in what

quantity, is a difficult task but needs to be done now to ensure properly targeted skills development.

## 2.8 Leadership

- the strategic leadership for the management of dementia in Shetland has not been sufficiently supported by either the health or the social care system. Dementia planning has been treated variously part of mental health strategy, subsumed into community planning processes, seen as part of broader community capacity development strategies or an imposed target from central government.
- resources available on the island from charitable sources have not been connected to a compelling joint strategy for modern approaches to addressing the increasing needs for supporting dementia
- planning appears to have been piecemeal with planning processes for important elements of island provision of services stalling in the face of differing views about priority or content of schemes
- for some in leadership roles there seems to be a fear that further development of modern responses to dementia need will struggle to make progress, because the next steps will involve engagement with a sceptical public.
- conflicts of interest and avoidance of challenge over these conflicts may have led to missed opportunities
- the role of senior executives in providing connected leadership in managing the staff processes, the political influence and the media fall out needs to be strengthened

## 2.9 Risk

- addressing risk at a number of levels would make a significant difference to future prospects
- an increase in the confidence of individual staff through education would reduce their perception of risk
- an improvement in the public understanding of dementia would decrease many of the political and reputational risks
- an understanding of shared risk would decrease the unhelpful high level of influence over outcomes for people with dementia from a narrow section of the total dementia pathway
- any complaint can in effect stall a whole system and this suggests that progress made to date on dementia needs embedding and further development as a matter of priority
- dementia being looked at as a sub-set of an impending mental *health* review rather than part of a broader public vision for community development is a significant leadership issue
- a failure to date to secure sufficient buy-in and clarity about evolving and shifting roles and responsibilities between the statutory services, the third sector and the public is a problem and though the new Dementia Partnership is a sound idea with a lot of potential, responsibilities and accountabilities between the Partnership and others seem unclear and social work appears to be largely excluded

## 2.10 Future-proofing

- overall there seems to be gap preventing the economic case for a strategic, inclusive and comprehensive approach to dementia (providing better care and support at less cost to statutory services) into practice and action.
- current planning processes may be worth reviewing to ensure they are sufficiently robust and nimble to identify and address need at the right level to provide the traction, detail and cultural shift needed to address this gap
- the way the future pattern of dementia is expressed and understood could be considered too vague to prompt the sort of dynamic, innovative and thoughtful response needed to deliver proactive rather than reactive planning for the future.

### 3 Recommendations

These are the main recommendations arising from the Deep Dive.

The Recommendations are intended to be taken as a whole. Each recommendation is self-contained and has its own value, but taken together we believe they provide a dynamic template for meeting the future needs of dementia on Shetland.

#### Recommendation 1 – Dementia Friendly Vision

We believe that there is a strong case for developing a single compelling vision to engage directly with the professional and public issues we have identified.

The current position in Shetland means the island could make significant progress by adopting a public commitment to becoming Dementia Friendly.

There are many different models being adopted for Dementia Friendly Communities in the UK but we suggest Shetland can unique develop its own approach through genuinely placing the professional staff and the public at the centre of thinking through what such a commitment means to individuals, to families, to communities and to agencies.

This would provide a fresh, human, non-bureaucratic gathering point for a dialogue about the immediate future which connects to the public in the language they use.

Whilst drawing the experience of others such a local, dialogue-based approach would address directly differences of perception and division over services and responsibilities.

In turn this would provide a starting point for the mobilisation of all the Island's resources– not about what is being lost but about developing resilient service change with community buy-in if necessary in the face of opposition; will shift balance from statutory provision to co-design and delivery; also increase joint working between statutory agencies and others such as Housing Associations whose value is currently underplayed.

It could if pursued with conviction provide a stimulating model for the co-

design of social provision more generally.

We recommend this approach replaces the planned commitment to undertake a dementia review as an integral part of a mental health review.

### Recommendation 2 – Mapping

Alongside a commitment to a compelling vision some practical steps also need to be taken quickly to provide data for action.

We recommend a comprehensive mapping exercise is undertaken to inform the development of future provision on the island. This would not need to be a long or complex process but it would need to be done transparently and would need the public commitment of key stakeholders.

The mapping would need to be designed to involve professionals of all disciplines and the public in mapping current models of care, resources, locations, staffing, processes and protocols and identifying options for future provision needed to meet current and future dementia needs.

This will involve potentially difficult discussions concerning dementia on its own, in the context of mental health, the context of reducing resources and of new models of community enablement and in the context of strategies for older people.

This would provide a creative map for future resources, with a commitment to action. The public should be central to this process in refining options as well as being involved in “normal” consultation processes,

External facilitation of the mapping process might be helpful. A clear timetable should be set for this work.

### Recommendation 3 – Leadership

Commitment to becoming Dementia Friendly will help provide a platform for shared leadership across organisational boundaries and historical divisions.

The leadership challenge goes beyond this commitment. Current senior staff, whether holding elected, non-executive or executive positions, need to act as visible agents of change (not just public service planners and reviewers) working alongside the community agents of change (for example families who are benefitting from new models of care or opponents of change) and pushing forward and testing out genuinely innovative packages of care.

Leadership in Shetland has particular challenges which make being bold potentially a complex and personally difficult route to take. More purposeful engagement with these largely hidden issues between senior staff and elected representatives about roles and responsibilities and support to achieve necessary change will be critical given the overall social and economic changes in Shetland.

Dementia could be used as a helpful focus in microcosm for moving these understandings forward. Integration at all levels is of key importance here.

There may be value in a Joint Islands approach with Orkney and Western Isles to dementia and to wider change, but only if this does not prevent a clear timetable of movement to a new deal on dementia within three years, with milestone dates within each year for dementia in Shetland

#### Recommendation 4 – Resources

Future dementia needs in Shetland require a fundamental reappraisal of what is meant by resources to meet dementia needs – financial and human.

At one level we recommend a zero-base budget approach to funding allocations for mental health, community provision and dementia. This will help focus on where financial resources are currently deployed (something which we found largely absent during our Deep Dive) with a view to challenging these deployments in terms of value and impact in supporting a fully functioning dementia-friendly island.

Done transparently this would also form part of the dialogue over what constitutes resources on the island and what knowledge and skills are needed where in future, with both the public and professionals involved in the process of identification and design.

Zero-based budgeting linked to a strong sense of place could help create momentum for change.

#### Recommendation 5 – Capacity Development

We recommend priority is given to addressing skills shortfalls in professional staff across all agencies and also to the reallocation and retraining of staff to fulfil community roles and to develop innovative support systems in the community.

New roles can be designed and would help reinforce new models of care but only if there is a sound currency of skills and a commitment to their development.

In Shetland current community capacity supporting people with dementia is complex and often hidden. The statutory agencies will need to adopt a more inclusive approach to capacity development, helping the public understand that they themselves are as critically important to dementia support as professional services have been.

A simple Skills Audit, including skills in the community, could form an early part of a shared commitment to becoming dementia friendly. The specific

recommendation here is for training needs to be based on a comprehensive skills and assets audit, to complement the mapping project, which should be commissioned to be undertaken independently of vested interests.

The outcome should be a clear programme of skills development and capacity building, to equip communities throughout Shetland, as well as in professional staff from whatever background or organisation, to the same levels of knowledge and practice.

Such an audit would help build recognition of the value of professional dementia-related knowledge across a broader range of people, improve individual confidence and competence and support a greater collective sense of purpose.

Consideration should be given to a single hub for training and knowledge development in dementia care, to support development and recognition of standards, behaviours and skills across boundaries and into communities. This would clearly complement a commitment to becoming truly dementia-friendly.

#### Recommendation 6 – Innovation

Innovation must be celebrated more and be more visible in the media and by use of other communication to counter negative framing of dementia on the Islands. This can be linked to other issues and challenges where a change in public attitudes and behaviour is supportive of improved health and life experiences for the population.

Recognition should be sought outside Shetland for innovation and charitable resources secured and deployed from within the Island and in partnership with agencies outside, such as the Life Changes Trust and the Big Lottery.

The possible role for an innovation fund to support retro-fitting of homes to make them dementia-friendly could for example be a worthwhile investment by the Shetland Development Charitable Trust in helping more people with dementia and their families maintain a sustainable independence and quality of life,

#### Recommendation 7 – Services

In respect of dementia-related disturbing behaviour, consideration should be given to a small unit of no more than 4 beds which can be made operational when required by specially-trained staff, normally deployed on other duties.

Key workers with appropriate authority to co-ordinate and make decisions across organisational boundaries would be instituted to support this behavioural and social symptomatic modification facility (this means an

expert team and a designed space where people with dementia can calm down, be comforted and supported while the staff and families who may have inadvertently precipitated the behaviour can themselves calm down and learn how to manage those behaviours going forward).

Disturbing behaviour in people with dementia is usually temporary and exacerbated by inexperienced responses from staff and families and poor design of facilities and care processes. Expatriating the person to mainland Scotland will not prevent reoccurrence of the behaviour when the person is returned home after calming down. There will be sufficient space in one of the existing care centres to develop this.

#### Recommendation 8 - Directory

Shetland should have a directory of Services on-line which includes clear information about the dementia pathway which will be of help to both the public, people with dementia, carers, the media and also those staff who appear not to understand or “agree with” the existing service provision.

This should be developed with or even by services users and be promoted on-line as a stand-alone site. Reference to nationally-available resources such as the 24 hour Dementia Helpline as well as local support and practical information should form part of what the site offers.

## **4 Conclusion**

We recognise that dementia is only one of many challenges facing Shetland. However getting dementia right could not just be of importance in itself but could also provide a way forward on other complex social challenges and long-term conditions on the Island.

We also recognise there are inevitably limitations for a Deep Dive undertaken over a limited time period within a specific budget, but we believe the analysis and the recommendations provided here constitute a forceful agenda for equipping Shetland to meet its future dementia needs.

Professor June Andrews

Mark Butler

October 2013

## **Annex A      Background and Context**

Strategic engagement with the implications of care of older people including those with dementia and related conditions has increased significantly, as awareness of the social and economic impact has become more widely understood. Longer-term demographic changes, with the implications of an older, more dependent population, have risen in importance in shaping policy development for health, housing and social care. Provision and support available locally to older people with dementia and other complex conditions and the need for new models of care are now a more immediately pressing issue in respect of funding, quality and delivery.

Dementia is a priority across the UK. In Scotland the launch of the National Dementia Strategy in 2010 provided a focus for work between the NHS and partners in local government and the voluntary sector with two national Progress Reports being published in June 2011 and 2012. The Scottish Government has developed a new dementia strategy to take effect in 2013. National strategies have tended so far to concentrate largely on quality improvement but DSDC is also involved in more critical and analytical work examining the cost-benefit of doing things well for older people and avoiding costly investment in changes or developments, for which there is little or no evidence of benefit or positive impact.

Dementia is a focus for development of standards and the auditing of those standards in NHS Health Boards and for the integration of health with social services. Dementia and cognitive impairment have been a prominent element (one of three specific areas highlighted) in the programme of inspections announced in 2011 to be undertaken by Health Improvement Scotland (HIS), and designed to focus on the care of older people in acute settings.

In respect of NHS Shetland and Shetland Islands Council there is a specific history to the wider provision of health and social care and the challenges offered by location which have shaped the nature and quality of dementia services and provision for older people, mental health and unscheduled care. In light of the refreshing of national strategy, this is a good time to take stock of the situation on Shetland in a proactive and systematic way. By commissioning an independent, action-focused approach, in the form a “deep dive”, Shetland will be able to understand quickly what further action might need to be taken to meet future expectations for improvement by external agencies and partners and to drive forward sound, evidence-based practice and capacity development in the way services are provided to local people. At one level Shetland is well on its way to being a dementia-friendly community with some clear positive signs and innovative practices. If capitalised on these could provide a sound basis for the future. However, in the absence of a clear public narrative on the direction services are taking, there will be a missed opportunity.

## **Annex B      Methodology, Timing and Process**

The approach commissioned by DSDC was to provide an independent assessment of the current strategies and provision related to the care of people with dementia within the NHS Shetland and Shetlands Island Council area and to provide a report on its fitness for purpose in relation to relevant evidence-based standards.

The focus was be on identifying key areas of strength, which can be built upon, and areas of potential risk, where further action might be recommended. The scope of the work covered all provision directly related to people with dementia, focusing in more detail on specific areas agreed with the clients which included supported housing, issues in respect of diagnosis, acute hospital challenges for management of dementia, management of episodes of disturbing behaviour, inter-professional relationships and sustainability of care centres.

The “deep dive” used an established methodology which has been developed over a period of years. It has been used most recently by DSDC in the last two years for clients including the Northern Ireland Government, a large County Council in England and two Health Boards. A Case Study on one of the Deep Dives can be found here <http://www.dementia.stir.ac.uk/case-studies/04-change-deep-dive>

The approach deliberately looks at strategic and practical issues together. The “deep dive” visit was conducted intensively over a short period of time with face to face meetings in Shetland over four days. In part it deliberately followed the direct experience of people with dementia and their carers through services and pathways from pre-diagnosis onwards. The methodology involves direct engagement with staff at all key points on this process, thus allowing important changes to be worked through with front-line staff at the time and unlocking immediate changes of demonstrable benefit in priority areas, based on evidence of what is known to work. This form of confidential coaching and advice was used extensively over the four days. In addition counselling of carers and relatives was included on this particular Deep Dive, both individually and in groups at the request of carers, as a result of interest stimulated by the Council and Health Board through the press, internet, and radio.

The assessment undertaken in September 2013 included the following elements:

- review of key documents and data
- structured interviews with key stakeholders
- sample visits to service providers and partners

The assessment was undertaken by two named individuals who have led other Deep Dives in the last two years:

- Professor June Andrews, Director of Dementia Services Development Centre, University of Stirling.
- Mark Butler, Director of Development (DSDC) and Director, The People Organisation Ltd

The Dementia Services Development Centre based at the University of Stirling is recognised internationally as a unique source of practical expertise on what works well in tackling the challenges offered by dementia and related conditions of old age to policy makers, to those professionals who care for older people, to carers and to older people themselves. Professor Andrews, as its Director since 2006, has established an international reputation as a leading expert in the field of dementia provision, its current practice and future delivery. Full profile and further details on DSDC at [www.dementia.stir.ac](http://www.dementia.stir.ac)

The People Organisation Ltd works with DSDC on issues of governance, development, system change and delivery. Mark Butler is a recognised expert on organisational change and people management and has held a number of policy and delivery roles within the public sector. Full profile available at [www.thepeopleorganisation.com](http://www.thepeopleorganisation.com)

The main outcomes of the assessment process as agreed at a meeting with the Chief Executive of NHS Shetland and senior clinical and management staff and representatives of the Shetland Islands Council

- a brief report of findings and recommendations, to be provided to the two Chief Executives of the Council and the Health Board
- a summary briefing presentation

Simon Bokor-Ingram, Interim Director of Community Care, acted as the main point of contact and facilitator for the framing and delivery of the assessment. He facilitated access to all key information and documentation needed to complete the assessment and identified key stakeholders who needed to be aware of the assessment and/or involved in the process. Professor Andrews was the lead contact for this work and takes overall responsibility for delivery of the assessment. All materials and correspondence relating to this work were to be sent to both [june.andrews@stir.ac.uk](mailto:june.andrews@stir.ac.uk) and [mark.butler@stir.ac.uk](mailto:mark.butler@stir.ac.uk).